Impact of End-Stage Renal Failure on the Everyday Life of Saudi Arabian Women

Eiman Mohammad Saleh Fatani

A Thesis submitted for the Degree of Doctor of Philosophy
Department of Sociology
University of Surrey
Guildford

© Eiman Fatani

March 2008
Abstract

This study is the first research conducted in the field of sociology of health and illness that explores the impact of chronic illness, specifically end-stage renal failure (ESRF), on Saudi women. In order to examine how traditional Saudi structures influence the illness and disability experience of Saudi women, this study explores distinctive socio-religious values of Saudi Arabia within the framework of western sociological concepts. The aims of this study are to explore gender-related issues that affect the various aspects of chronically ill and disabled Saudi women's life; to examine the impact ESRF has on their quality of life, as well as their perceptions of themselves and their illness (body image, self-concept and identity) that may prove to be detrimental to their family care-giving roles and relationships; and to determine how they manage their everyday life. Although these concepts are highlighted in western sociological literature, this study critically re-evaluates them in the light of the socio-cultural differences found in Saudi society.

In Phase I, a survey questionnaire was used to obtain socio-demographic information about all female patients (n=216) undergoing haemodialysis (HD) at the Jeddah Kidney Centre over a three month period. Following exclusion of all non-Saudi women and all Saudi women under age 24 years and over age 59 years, this produced a sampling frame of 150 Saudi women between the ages of 24-59 years, from which the sample for interview was selected by 'systematic sampling'. In Phase II, a qualitative method was utilized to obtain in-depth data from participants in their own words about their illness experience. The sample comprised 50 Saudi women (age 24-59 years) mainly from a low socio-economic background undergoing haemodialysis who were interviewed in-depth on two occasions approximately three weeks apart. A ‘grounded theory’ approach was used to analyse the recurring patterns and themes explored in the data.

The findings indicate that the gender based social structure of Saudi Arabia that upholds the family and its traditions acts as a socio-cultural constraint to chronically ill women with ESRF. The societal perpetuation of ideal roles of wife and mother and the imposition of rigid expectations for women conflicted with the realities of living with chronic illness that disrupted their traditional family roles and relationships, distorted their self-perception and ultimately threatened their identity. These women’s increased dependence on their female relatives to provide domestic support further weakened their status within the family and eventually sabotaged their efforts to maintain normality in their life.

The findings further suggest that the gender based issues arising out of socio-religious values of Saudi society regarding female dependence on their male legal guardians and male relatives had a negative impact on the economic aspect of life for Saudi women with ESRF. Since these women primarily came from a low income background, the onset of ESRF placed additional financial constraints on their resources and sources of support that further diminished their quality of life. These findings suggest that the Saudi social structure actually disabled chronically ill Saudi women from managing their everyday life.

In conclusion, this study proposes policy implications that the Saudi State needs to implement in order to improve the quality of life of women with ESRF and their
families, such as, increased financial resources, improved dialysis facilities, and transportation services; along with home healthcare.
ACKNOWLEDGEMENTS

Thanks to my Supervisor Professor Sara Arber whose academic advice has been valuable.

Special thanks to my husband Abass A. Kattan for his support and understanding throughout my years of research; and to my family and friends for all their prayers.

Thanks to Dr. Sagar for his cooperation.

Sincere appreciation to all the women who, despite their difficulties with ESRF still found the time to share their experiences with me; and to the JKC medical and administrative staff for their support.
DEDICATION

In memory of my loving parents
Mohammad Saleh D. Fatani and Zain M. Kurdi,
my sister Dr. Ebtissam, and my brother Mohammad Rayed
God bless their souls.
Chapter Four:
Saudi Society, Family Structure and the Position of Women 47
Geographical information on Saudi Arabia 47
  Demography 47
Development plans for Saudi Arabia's modernization 48
Saudi family structure 50
Status of women in Saudi society 53
Saudi women’s gender-based roles 55
Identity of Saudi women 56
  Single/Shared disability identity for Saudi women 58
Conclusion 58

Part II. Methodology

Chapter Five:
Quantitative Survey of Women Undergoing Haemodialysis 61
  Using multiple methods 61
  Population under investigation 62
  Designing and developing the survey questionnaire 62
    Piloting the questionnaire 63
  Ethical considerations 63
  Implementing the survey questionnaire 64
  Analysis of survey data: Socio-demographic profile for women undergoing haemodialysis at JKC 65
  Conclusion 73

Chapter Six:
Qualitative Research Design 75
  The rationale for using qualitative interviews 75
  Aim of the study and research questions 76
  Sample 77
  Ethical issues in qualitative research 77
  Piloting the qualitative interviews 79
  Interviewing female medical and nursing practitioners 80
  Conducting repeated in-depth interviews 80
    Structure of first interviews 81
    Location and time of first interviews 81
    Logistical problems of first interviews 82
    Structure of second interviews 83
    Location and time of second interviews 84
    Logistical problems of second interviews 84
  Socio-cultural characteristics encountered during the second Interviews 85
    Social interaction 86
    Verbal and non-verbal communication 87
    Concept of time 88
Part III. Data Analysis

Chapter Seven:
The Process of Making Sense of ESRF for Saudi Women

Impediments to making sense of illness
Lack of awareness and understanding
Religious and cultural beliefs

Recognizing the illness
Alternating between fear and comfort

Living with the reality of the illness: identity and self-concept

Changes in physical appearance
Single women
Married and separated women
Divorced and widowed women
Summary

Changes in physical ability

Changes in cognitive ability

Fear of the uncertainty of the future

Adapting to the illness

Conclusion

Chapter Eight:
The Importance of Religious, Medical and Economic Resources for Saudi Women with ESRF

Religious resources
Medical resources
Income
Transportation for dialysis
Accommodation and change in living arrangements
Separated women
Divorced women
Widowed women
Implications of moving to live with extended family members

Conclusion
## Chapter Nine:
The Importance of Family Support for Saudi Women with ESRF

### Inter-personal relationships
- Blood-related marriage
- Divorce and blood-related in-laws

### Domestic Support
- Single women
- Married women
- Previously married women
- Motherhood
  - Women only with daughters age 12 years old or less
  - Women with daughters age 13 years old or more
  - Women with married daughters

### Non-domestic support
- Conclusion

## Chapter Ten:
Disruption of Family Care-giving Roles and Relationships due to ESRF

### Lack of communication and social participation
- Young single women: age group (a) (24-28 years)
- Other single women: age group (b) (29-35 years)
- Ever married women with children

### Loss of marital intimacy
- Married and separated women
- Divorced and widowed women

### Loss of domestic authority
- Loss of privacy

### Conclusion

## Chapter Eleven:
Saudi Women's Responses to Managing Life with ESRF

### Denial and/or minimization of symptoms
- Denial of changes in physical appearance
- Denial of physical limitations by undertaking ‘normal’ domestic responsibility
- Denial of medical complications

### Acknowledgement of physical limitations and integration
- Young single women in age group (a)
- All other women

### Forming new relationships with fellow patients

### Trial and error

### Dependence on others
- Restructuring relationships
  - Role reversal
Appendices

Appendix A: Map of Saudi Arabia 219
Appendix B: Letter of introduction (Translated English version) 220
Appendix B(i): Letter of introduction (Arabic version) 221
Appendix C: Consent form (Translated English version) 222
Appendix C(i): Consent form (Arabic version) 223
Appendix D: Survey questionnaire (Translated English version) 224
Appendix D(i): Survey questionnaire (Arabic version) 229
Appendix E: Interview guide (Translated English version) 234
Appendix E(i): Interview guide (Arabic version) 236
Appendix F: Personal characteristics of Saudi women interviewed 238
Appendix G: Glossary 246
Appendix H: Abbreviations used 248
## List of Tables and Figures

<table>
<thead>
<tr>
<th>Table</th>
<th>Title</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>5.1</td>
<td>Demographic profile of women undergoing haemodialysis</td>
<td>68</td>
</tr>
<tr>
<td>5.2</td>
<td>Information of all women undergoing haemodialysis</td>
<td>71</td>
</tr>
<tr>
<td>5.3</td>
<td>Household composition of according to marital status</td>
<td>72</td>
</tr>
<tr>
<td>5.4</td>
<td>Extent of physical and psychological inference</td>
<td>73</td>
</tr>
<tr>
<td>6.1</td>
<td>Demographic characteristics of women interviewed according to age group</td>
<td>95</td>
</tr>
<tr>
<td>6.2</td>
<td>Household composition of interviewed participants according to marital status</td>
<td>96</td>
</tr>
<tr>
<td>7.1</td>
<td>Age group and marital status of sample members</td>
<td>106</td>
</tr>
<tr>
<td>8.1</td>
<td>The accommodation of previously married participants</td>
<td>126</td>
</tr>
<tr>
<td>9.1</td>
<td>Number of ever married participants with daughters who provide domestic support</td>
<td>143</td>
</tr>
<tr>
<td></td>
<td>Key family relationships of women within Saudi family Structure</td>
<td>52</td>
</tr>
<tr>
<td>8.1</td>
<td>Types of support resources and sources that provide them</td>
<td>117</td>
</tr>
<tr>
<td>9.1</td>
<td>Social support and the sources that provide it</td>
<td>134</td>
</tr>
</tbody>
</table>
Preface

The aim of this study is to focus on how chronic illness, specifically, end-stage renal failure (ESRF) and its treatment, haemodialysis (HD) affect the lives of Saudi women. This study explores gender issues that are peculiar to Saudi society and how they disable the lives of chronically ill women. A structural approach and interactionism are the two sociological perspectives used to analyse factors in Saudi society that have disabling effects on chronically ill Saudi women; as well as examine how these women perceive themselves and their illness experience.

My research focuses on issues that affect the illness experience of Saudi women with ESRF who as recipients of government subsidized medical care, were identified as belonging to the low income category. A qualitative approach, utilizing in-depth interviews, was used to examine the daily challenges these women encounter while attempting to manage their life. The research specifically explores how the traditional structure of Saudi society shapes the types of sources and resources available to Saudi women with ESRF and the extent to which the lack thereof impedes their quality of life. The sources available to these women are primarily based on the traditional Saudi family structure and the socio-religious beliefs defining responsibility according to gender.

The main reasons for undertaking this study stem from my professional experience: first, as a medical social worker dealing with chronically ill women in Saudi Arabia; and second, as a lecturer in the area of medical sociology for sociology students and a supervisor for hospital field work training for students in the Sociology department at King Abdulaziz University in Jeddah since 1989. As a lecturer, I discovered that there is no literature or research studies from the fields of social science dealing with Saudi women suffering from chronic illness. Although there are numerous studies involving chronic illness in western literature, these theoretical concepts and approaches are not explored within the context of Saudi religious, social and cultural background. I hope to provide scientists in the field of health and illness with a clearer insight into the lives of chronically ill disabled Saudi women. I believe that I can bring a vital perspective to this study as a Saudi woman who personally understands the social dynamics of living in a traditionally Muslim society that shares some modern characteristics of western society.

For practical reasons, my study specifically focuses on Saudi women suffering from ESRF rather than other chronic illnesses. Jeddah is the site of the Jeddah Kidney Centre (JKC) which is the largest government subsidized kidney dialysis centre in Saudi Arabia, and where the majority of renal patients in Jeddah are treated free of charge. This is an ideal setting for my research because a large sample of female patients is readily available at the kidney centre for interviews. Convenience is also a factor since I reside and work in Jeddah.

After consulting with medical professionals and speaking with these women about their illness experience, I realized that there is an urgent need to explore the various issues concerning the impact ESRF has on their quality of life. The more details these women revealed, the more responsible I felt in conveying their circumstances to those people who influence and shape policy. I found that policymakers are unaware of the impact chronic illness has on various aspects of life for low income Saudi women, as well as the overall effect it has on their family. Since this
unawareness is the primary reason for the lack of services provided to these women, I decided to use my research to raise national awareness about the issues involving chronically ill and disabled Saudi women. By generating awareness, I also hope to influence policy implementation that will address the various needs of these women.

Outline of the thesis

Part I. Literature Review

Chapter 1: Physical Limitations Imposed by ESRF and Haemodialysis

This chapter provides medical background information about end-stage renal failure (ESRF), and haemodialysis (HD). The profound effects of ESRF on sufferers, in particular, the physiological and psycho-social effects of dialysis are discussed. An overview of the healthcare system and the demographic characteristics of patients with ESRF in Saudi Arabia is also provided.

Chapter 2: Developing an Understanding of Chronic Illness

This chapter reviews the theoretical approaches that stem from the political, economic and social ideas during the 19th and 20th centuries that are found in western literature on sociology of health and illness. It specifically explores the development of the structural and interactionist theories, concepts and models that sociologists have employed in order to better understand chronic illness and the illness experience.

Chapter 3: Approaches to Defining Disability

This chapter reviews the different perspectives that underlie the models of disability studies found in western literature. It examines the contemporary disability movement's influence in redefining disability; and discusses it from the perspective of both disability theorists who are influenced by the structural approach; and sociologists who more often use an interactionist approach to understanding disability identity.

Chapter 4: Saudi Society, Family Structure and the Position of Women

The aim of this chapter is to concentrate on the socio-cultural aspects of Saudi Arabia; how they affect the status of Saudi women; and how the socio-religious norms shape their identity. This information is necessary as a basis for understanding a country that is steeped in religious and traditional customs, despite the impact modernity has on the society. The chapter specifically examines the roles and relationships of Saudi women who remain bound by tradition in spite of modern changes. Cultural differences are also explored to identify the relevant nature of issues highlighted in western literature.
Part II. Methodology

The methodology section is divided into two chapters: quantitative and qualitative research design.

Chapter 5: Quantitative Survey of Women Undergoing Haemodialysis
This chapter discusses the methodological procedures used in designing, developing, piloting and implementing the survey questionnaire; population under investigation; and ethical considerations. It discusses the survey conducted to collect a complete and concise census of all 216 women suffering from ESRF and undergoing HD therapy. A questionnaire was administered to all women attending any of the four HD therapy sessions at the Jeddah Kidney Centre (JKC) during a three-month period. SPSS was employed in the statistical analysis of the survey data.

Chapter 6: Qualitative Research Design
This chapter addresses the qualitative method applied in my study that includes unstructured interviews which allow me to obtain in-depth information from participants in their own words. Fifty Saudi women between the ages of 24-59 were interviewed on two occasions. All interviews were tape recorded, transcribed and translated into the English language. This chapter also discusses pilot study, rational for conducting repeated interviews, ethical issues and issues related to the sensitivity of the subject.

Part III. Data Analysis

This section contains five-interrelated chapters that analyse the main concepts elicited from the women’s narratives. The narratives aided in the understanding of how chronically ill Saudi women interpret the disruptive factors caused by ESRF, how they manage their every day life and ultimately make sense of their illness. In order to examine the whole illness experience, the interactionist approach was implemented to explore the various effects chronic illness has on their life.

Chapter 7: The Process of Making Sense of ESRF for Saudi women
This chapter explores how Saudi women suffering from ESRF perceive themselves with regard to the physical, emotional and psychological changes they experienced as they attempted to make sense of their illness. It discusses the socio-religious factors that impede these women from making sense of their illness: lack of awareness and understanding of their illness, and religious and cultural beliefs. This chapter examines the various phases that these women go through while trying to live with the reality of the illness and adapt to the illness.

Chapter 8: Constraints on Support Resources for Saudi Women with ESRF
This chapter critically analyses how various sources of support affect the quality of life for Saudi women suffering from ESRF. It focuses on how support resources, such as religious, medical and economic, enable participants to manage their lives. It explores how variables such as: the participants' marital status, motherhood (having children), income and their health condition, determine women's need for
specific resources. Sources that provide these support resources are divided into three categories: the State, family and acquaintances. This chapter shows how dependency on these sources of support is shaped by the socio-cultural norms of Saudi society.

Chapter 9: Family Support and its Importance to Saudi women with ESRF

This chapter explores aspects of family support and analyses their importance to Saudi women with ESRF. Family support includes inter-personal relationships and practical support. Practical support is sub-divided into domestic (household chores, childcare and personal care) and non-domestic (transportation, escorting, running errands and shopping) support. This chapter illustrates how the required needs of each of the participants are related to socio-demographic variables such as: their age, marital status, motherhood and income. This chapter also examines how growing dependency shifts the dynamics of inter-personal relationships and how perpetual responsibilities to provide practical support for women with ESRF placed upon both female and male relatives strain family support. This chapter reveals how this strain eventually diminishes these women's quality of life.

Chapter 10: Disruption of Family Care-giving Roles and Relationships of Saudi Women with ESRF

This chapter examines the factors that disrupt the traditional roles and relationships of Saudi women with ESRF; and the nature and extent of this disruption. This chapter explores the impact of these disruptive factors on the emotional well-being of these women which depends upon companionship, comfort, encouragement and reassurance from all family members. The multiple and varied roles and relationships these women have depending upon their marital and motherhood status are discussed within Saudi socio-religious context that shapes the expectations that women have of themselves. This chapter highlights how their loss of control over aspects in their life sabotages their traditional roles and relationships that define who they are within the family and society.

Chapter 11: Saudi Women's Responses to Managing Life with ESRF

The main purpose of this chapter is to examine how Saudi women with ESRF come to terms with their competing demands in order to adapt to their illness and their new way of life. It explores the success or failure of particular actions used by these women in managing various aspects of their lives, such as, religion, health, financial and social; in order to maintain normality. This chapter discusses how their altered way of life redefines their understanding of normality in terms of what they 'can do now', instead of what they 'used to be able to do' when they were healthy.

Part IV. Discussion and Conclusion

Chapter 12: Impact of ESRF on Saudi Women's Everyday Life

This chapter analyses the western theoretical approaches to understanding chronic illness to determine their applicability to Saudi women's experience with ESRF. It discusses how the structuralist approach is a relevant approach to this study when exploring how the impact of the structure of Saudi society and its socio-economic
institutions. However, this chapter further discusses how the structural approach limits its definition of disability to a social problem and disregards the nature of chronic illness and the sufferer's perspective. It then explores the relevance of applying the interactionist approach to analysing the affect of ESRF on the everyday life of Saudi women where the focus is on the individual sufferer's experience with chronic illness. It reveals how a 'hybrid' perspective is utilized in this study so as to fully understand chronic illness as it applies to both Saudi society and Saudi women.

Chapter 13: Conclusions, Policy Implications and Reflections

This chapter presents the conclusions of the study. The research findings should assist policymakers in creating and implementing new policies and procedures that will meet the global standards for improving the quality of life for chronically ill and disabled women in Saudi Arabia. Possible areas that may need further investigation are also discussed. The need for greater social awareness within Saudi society is discussed with the intent to promote a national policy that accommodates the needs of chronically ill Saudi women and eliminates socio-economic barriers that disable them from managing their everyday life.
PART I
LITERATURE REVIEW
In order to understand how end-stage renal failure (ESRF) also known as chronic renal failure (CRF) and renal replacement therapy, i.e. dialysis, imposes physical limitations that change the way of life for chronically ill Saudi women, it is relevant to examine the disease and its medical treatment. The aim of this chapter is therefore to provide descriptive background information about ESRF and dialysis. The healthcare system in Saudi Arabia is also discussed to shed light on the status of haemodialysis (HD) patients.

Functions of the kidney

The two kidneys in the human body are located bilaterally in the lower abdomen: ‘The kidneys are paired organs lying on the posterior abdominal wall behind the peritoneum’ (El-Said, 1992: 7), forming part of the urinary tract system that includes the ureters, bladder and urethra. The bean-shaped structure comprises of an outer layer called the cortex, and an inner one called the medulla. The medulla contains the functional units of the kidney, called nephrons, each of which contains glomerular capillaries that are surrounded by the Bowman’s capsule. The capillaries and the Bowman’s capsule are also termed the glomerulus, which 'acts as an ultrafilter' to remove 'soluters' (Berkow, 1982: 1481). These solutes are 'end products of protein metabolism: urea, uric acid, creatinine, phosphates, and sulphates' (El-Said, 1992: 11).

The most common function of the kidney is the removal of 'waste products from the blood' (Falvo, 1999: 311). It is important to note that the kidney filters a sizeable amount of blood each day. Approximately one quarter of the body’s blood passes through the kidney (Falvo, 1999: 311), with the formation of a glomerular filtrate of 180 litres every twenty-four hours (El-Said, 1992: 11). The kidney also filters solutes and then reabsorbs them into the blood stream. These include sugar, amino acids (which are also the building blocks of protein), and electrolytes - sodium and potassium (which are important for muscle contractions, heart function and water balance) (El-Said, 1992: 11-12). Regulation of blood pressure is an additional function of the kidney. This is undertaken by the juxtaglomerular complex, which includes the functional unit of the glomerular arterioles, the distal convoluted tubule, and the secretory granules of the arterioles. Together they form the product renin that is seen to have an important role in controlling blood pressure (El-Said, 1992: 9). Further functions of the kidney include the release of the product 'erythropoietin which stimulates the bone-marrow to produce red cells' (p. 12) as well as 'calcium absorption from the intestine' (Falvo, 1999: 313). These multiple functions illustrate the central role the kidney has in the human body.

When kidneys fail to function and satisfy the body's need to filter the blood and excrete excessive fluids and wastes, renal damage occurs, which in turn leads to ESRF. There are several causes for ESRF: acute renal failure left uncorrected; kidney disease (i.e., glomerulonephritis); or systemic disease (i.e., diabetes, arteriosclerosis). The chronic nature of ESRF causes irreversible damage to the kidneys which is in itself life-threatening. However, patients do not readily
associate features symptomatic of chronic renal failure with renal disease and can easily mistake them for temporary conditions. One of the most common symptoms of renal failure that can be attributed to several non-kidney related factors such as pregnancy, pelvic tumours or even exposure to cold, is pain in the lower abdomen. Other symptoms are polyurea and oliguria: the increased or decreased volume of urine. In each case the symptoms can be misinterpreted to be the result of compulsive water drinking or diminished intake of fluid. Hematuria, (the passage of blood in urine), is also an indication of renal failure that at times can be misinterpreted for tumours or traumas (El-Said, 1992: 13-15). These misinterpretations may delay patients from visiting the hospital or simply consulting a healthcare professional. However, once renal failure reaches an advanced stage, 'clinical manifestations start to make their appearance, sometimes in rapid succession' (El-Said, 1992: 72), the patient may have to go straight to dialysis treatment after the onset of symptoms.

Complications caused by kidney failure

Since the role of the kidney 'has an impact on all other organ systems' (Falvo, 1999: 317), when it fails, other clinical manifestations appear: the gastrointestinal system manifests a series of setbacks to the mouth (e.g. the taste of ammonia, bleeding gums), stomach (e.g. nausea, vomiting), and intestine (constipation, diarrhoea); the cardiovascular system may suffer hypertension, visual disturbances due to the narrowing of the retinal arteries, or even heart failure; the respiratory system is affected by deep sighing respiration and chest infections; the cutaneous system manifests yellowish discoloration of the skin, edema and/or bruises; and the nervous system exhibits headache, fatigue, dizziness, insomnia at nights, somnolence during the day, depression, convulsions, tremors, muscle twitches, cramps, confusion, sensory loss and motor weakness of the lower limbs. The other systems that are affected are: the skeletal system which manifests a demineralization of bones; the urinary system which suffers polyurea followed by oliguria and anuria; the genital system dysfunctions include amenorrhea in females and impotence in men; and finally, the haematological system that is affected by anaemia (causing depression of bone-marrow, shortage of red blood cells, and a bleeding tendency). Not only are these body systems greatly affected, the water and electrolyte balance results in salt and water retention and depletion; and changes in the level of serum potassium occur (El-Said, 1992: 71-75).

Dialysis therapy

When the body suffers from ESRF, the patient is faced with two possibilities: kidney transplant or dialysis, also known as renal replacement therapy (El-Said, 1992: 81). Transplantation is considered to be the best option; however the process of kidney transplants may be a long and unfruitful one due to the shortage of compatible organs (O'Callaghan and Brenner, 2000: 96) and a long waiting list of patients. There is also the serious problem of a patient's body subsequently rejecting the donated organ. These complications are the underlying reasons for more patients receiving renal replacement therapy.

Renal replacement therapy includes two types of dialysis: peritoneal dialysis and haemodialysis, of which the latter is the concern of my thesis. However, a brief
overview of peritoneal dialysis will be included to highlight the differences between the two treatments.

**Peritoneal dialysis**

The main advantage of peritoneal dialysis is that it is more accessible for those patients who have poor vascular access, i.e., elderly diabetic patients, very young children and patients with cardiovascular disease. There are three types of peritoneal dialysis: the continuous ambulatory, continuous cycler-assisted and intermittent peritoneal dialysis (El-Said, 1992: 89-90). Each type has its own separate procedure; but they also share a common one where a catheter is implanted through the abdomen to reach the peritoneum. It is through this catheter that the dialysate (a fluid which helps remove waste particles from the blood) is carried into the peritoneal cavities. The peritoneal membrane aids the process of filtration, as 'electrolytes and other substances diffuse across [from the blood] until equilibrium is reached' (O’Callaghan and Brenner, 2000: 97). This process usually takes four to eight hours during which the catheter is clamped. Following this period of time, the catheter is unclamped to drain the dialysate with the waste product from the body (Falvo, 1999: 322). Peritoneal dialysis is cited for having other advantages: there is no blood loss; it allows the patient to be mobile; is less expensive; and requires less complex equipment and specialized personnel (Leibrandt, 1983: 787).

There are several disadvantages associated with peritoneal dialysis. At times, complications cause a patient to forego peritoneal dialysis and undergo haemodialysis. There are two main reasons for this. The first one is the contamination of the catheter, which usually results in the prevention of further treatments. The second reason is that damage of the peritoneum through infection and dialysate concentration causes loss of the peritoneum membrane function that leaves the patient with no choice but to change to haemodialysis (Leibrandt, 1983: 787). Other disadvantages are that peritoneal dialysis is not as effective and is more time consuming than haemodialysis (El-Said, 1992: 89). Under peritoneal dialysis, more hours of maintenance treatment is spent than is required with haemodialysis. The former requires patients to ‘instill a fresh 2L of dialysate every 4h...around three to four exchanges are used each day’ (O’Callaghan and Brenner, 2000: 99) as opposed to haemodialysis that requires 3 to 5 hours per treatment (Leibrandt, 1983: 787), only three times per week.

**Haemodialysis**

Haemodialysis is the more common type of renal replacement therapy for patients with ESRF. Patients are attached to what is known as an ‘artificial kidney machine’, also known as a ‘dialyzer’ which ‘filters the blood to remove waste products and excess fluid’ (Falvo, 1999: 324). Generally the machine has two main parts, ‘one for the individual’s blood and one for the dialysate solution’ (p. 324) ‘with electrolyte composition nearly similar to that of normal plasma passing on the other side’ (El-Said, 1992: 83) which are separated by a synthetic semipermeable membrane. What initially alarms the chronic patient is the appearance of the machine, with its rather overwhelming ‘series of blood pumps, with pressure monitor and bubble detectors and a proportionating unit, also with pressure monitors and blood leak detectors’ (Kumar and Clark, 1998: 581). However, this rather complicated looking machine actually has a simple basis by which it functions.
There is a continuous process of pumping fluids in opposite directions: blood on one side of the membrane and dialyzed fluid on the other (O’Callaghan and Brenner, 2000: 97). The semipermeable membrane prevents blood and important substances from passing through, while allowing waste products to be ‘washed away’ (Falvo, 1999: 324). The purpose of this ultrafiltration process is to maintain equilibrium between the blood and fluid by modifying the speed with which the two fluids are being pumped: 'the amount of fluid removed by ultrafiltration is removed by altering the hydrostatic pressure of the blood compared with that of the dialyzed fluid' (O’Callaghan and Brenner, 2000:97). By the end of this process, the 'dry weight' of the patient should be attained (EI-Said, 1992: 84). Frequency and length of haemodialysis can be performed either three times a week for three to six hour sessions or daily for two hour sessions (Falvo, 1999: 325).

Haemodialysis usually requires two points of access to the patient’s blood: 'one to remove blood and one to return it in from the dialyzer' (O’Callaghan and Brenner, 2000: 97). The blood is accessed in one of three different ways: external arteriovenous shunt (least commonly used), graft, and internal arteriovenous fistula (most commonly used) (Falvo, 1999: 324). The first way requires a synthetic external tube to connect the two points of access. The other two ways require surgery where either a graft is implanted to connect an artery and vein or where a fistula (opening) is created when an artery is joined to a vein underneath the skin (p. 324).

**Effects of haemodialysis**

Although the whole dialysis process is 'painless', there are times when complications occur from the haemodialysis that range from the common and mild (hypotension, cramps, nausea, vomiting, headache, anaemia, loss of sensation, weakness in the arm and legs) (Falvo, 1999: 326), to the technical problems of the access site (infection in shunts or fistulae and thrombosis), to the more serious complications (intracranial bleeding, air embolism and heart failure) that can result in death (EI-Said, 1992: 84-8). Patients who have been undergoing haemodialysis over a long period of time often develop some of these complications. Other medical conditions, i.e., hypertension and diabetes can also affect the success of the treatment (Falvo, 1999: 317).

The majority of ESRF patients remain on haemodialysis for the remainder of their life unless they receive a renal transplant. This prolonged treatment causes physical changes that are difficult to conceal, i.e., enlarged vein in arm, discolouration of skin and teeth and uremia (build up of waste in the blood that causes foul body odour), that can eventually lead to a negative impact on body-image and self-esteem; which in turn, leads to many psychosocial implications, i.e., insomnia and mental cloudiness; anxiety, despair, anger, etc. that impede an individual’s daily management of his or her life (Falvo, 1999: 319); and imposes lifestyle changes that have a profound effect on roles and relationships which has its own psychosocial implications, i.e., isolation, depression, etc.

The following section includes an overview of the healthcare system in Saudi Arabia, which sheds light on the status of haemodialysis patients.
Overview of the healthcare system in Saudi Arabia

The healthcare sector is an integral part of Saudi Arabia’s Social Development Plan, that requires strategic planning and coordination every five years (Ministry of Planning (MOEP), Kingdom of Saudi Arabia (KSA), 2000-4: 287). Various objectives, policies and programs of the healthcare system are continually being 'upgraded and enhanced' (p. 289). This includes issues that concern the 'reduction of mortality rates', 'applying quality control programs', 'increasing of the number of hospital beds'; and 'Saudization of the health sector manpower' (pp. 289-290).

The continuous decline in cases of diphtheria, poliomyelitis and malaria indicates the success of programs dealing with the control and prevention of infectious and endemic diseases (MOEP, 2000-4: 281). On the whole, the development of the Saudi healthcare sector has been a response partly due to the needs of the growing population.

The government is also attempting to meet the changing healthcare needs of its citizens by building hospitals, equipping them with advanced medical technological equipment and recruiting foreign skilled professionals from neighbouring Arab States in order to reinforce the insufficient number of Saudi healthcare professionals (MOEP, 2000-4: 290). There were 218 hospitals and 30,489 beds in the Ministry of Health in 2006 (Ministry of Health, (MOH) 2006: 134). In particular, the number of artificial kidney centres in Saudi Arabia increased from one in 1971 to 160 by 2006; comprising 111 (Ministry of Health), 19 (other government sectors) and 30 (private sector), providing 2,262 haemodialysis machines for 8,761 ESRF patients (MOH, 2006: 277).

The Saudization plan, which aims to increase the number of Saudi healthcare professionals, was the impetus for providing government scholarship programs to educate and train Saudis abroad since the efficiency of the delivery of health services requires familiarity with the language, socio-cultural values and traditions of the country. Also, the effective communication between health workers and service recipients is paramount (MOEP, 2005-9: 430). This led to the increase in the number of Saudi physicians from 3095 in 2002 to 3773 in 2006; and an increase in the number of Saudi nurses from 10,339 to 17,068 (MOH, 2006: 103).

The Ministry of Health (MOH) is a major government agency in Saudi Arabia that finances and supervises the healthcare needs of Saudi citizens. Fifty-eight percent of all hospitals and medical centres within Saudi Arabia are managed, regulated and funded by the Ministry of Health (MOEP, 2000-4: 426). All Saudi citizens have access to these facilities free of charge. Seventy-five per cent of the total number of patients are treated in MOH facilities (Ministry of Economy and Planning, 2005-9: 426). The remaining 25% of patients are treated by other government facilities, i.e., Ministry of Defence and Aviation, National Guard, Social Insurance, etc.

Status of haemodialysis patients in Saudi Arabia

According to the Saudi Centre for Organ Transplantation (SCOT) (MOH, 2006: 47), which is the central body for coordinating renal replacement therapy under the auspices of MOH, the attributed causes of ESRD are: unknown aetiology in 1593
patients (18.2%); diabetic nephropathy in 2479 patients (28.3%); hypertensive nephropathy in 2940 patients (33.6%); primary glomerular disease in 633 patients (7.2%); hereditary renal disease in 192 patients (2.2%); obstructive uropathy in 222 patients (2.5%); primary Tubulo-interstitial disease in 78 patients (0.9%); vasculitis in 105 patients (1.2%); congenital malformation in 206 patients (2.4%); pregnancy related in 34 patients (0.4%); other reasons in 279 patients (3.2%). Out of the 8,761 patients undergoing haemodialysis in 2006, about 18% are on an active waiting list for renal transplantation and 20% are on a waiting list for work-up renal transplantation (p. 47). Among haemodialysis patients, males (53.1%) slightly outnumber females (46.9%).

The 2006 statistics indicate that there are 8,761 patients currently undergoing haemodialysis in Saudi Arabia with 71.5% of this total number being treated in MOH medical facilities. Renal failure is on the rise in Saudi Arabia and it is estimated that there will be an average annual increase of 7.8% that will lead to a number exceeding 11,000 haemodialysis patients by the year 2010 (MOH, SCOT report, 2006: 9). These 8,761 patients are distributed according to nationality, gender, and age: 7,584 (86.6%) are Saudis and 1177 (13.4%) are non-Saudis; 52.9% males and 47.1% females; 111 patients are less than 15 years, 606 patients are between 16-25 years, 6183 patients are between 26-65 years, 1375 patients are between 66-75 years, and 507 patients are over 75 years. Thus, 8,761 patients who are considered to be in their most socially active and productive years of life because they are between the ages of 26-45 years, are instead inflicted with ESRF and undergoing dialysis (pp. 43-44).

The estimated average annual increase of 7.8% of ESRF cases among Saudis is a clear indication of a health problem that must be addressed by the State and involve community participation in generating public awareness.

Conclusion

It is crucial to explore the effects of haemodialysis on Saudi women and how it drastically changes their way of life. Since their life includes both medical treatment and social interaction, the psychosocial implications of ESRF as well as the physical changes must be examined. The physical limitations imposed upon them by ESRF disables them from performing necessary tasks and family responsibilities. In addition, the emotional and social well-being is eventually impeded when these women are no longer physically able to fulfil their roles and relationships. Haemodialysis treatment, physical changes and psychosocial implications causing changes in the way of life have a circular effect. Thus, healthcare professionals and agencies have to be aware of how both ESRF and its treatment affect all aspects of Saudi women's life.

The majority of ESRF patients undergoing haemodialysis in Saudi Arabia consist of the 26-65 year age group. The impact of ESRF on Saudi women and their families requires the Saudi government to intervene on a greater level to improve their quality of life. A more comprehensive program that informs the community about this chronic disease and sensitizes them to the need for organ transplants; and a government policy for providing social services and financial support as well as healthcare was to be designed and implemented.
Chapter Two
Developing an Understanding of Chronic Illness

The main focus of this chapter is to explore the development of theories, concepts and models that sociologists have employed in order to better understand chronic illness and the illness experience. This chapter reviews the theoretical approaches that are found within the literature on sociology of health and illness. It examines a variety of sociological theories that stem from the political, economic and social ideas of western society during the 19th and 20th centuries. During the early period, health and illness was approached purely from a biomedical perspective. However, when changes in the social structures of modern western society, e.g., urbanization and industrialization took place, the medico-centric viewpoint of the practitioners was dominant and ignored the social factors that influence medicine. As the biological approach was increasingly criticized, medical sociologists separated themselves from medicine and developed theories from a social perspective. Sociologists then focused on the 'meaning of illness at the expense of the bodily experience' (Annandale, 1998: 4), where biological concerns were disregarded and primarily social factors were considered.

Since then, sociological theory has evolved into integrating the biological reality with the social experience of the ill person and sociologists realized that the approach used to analyse the illness experience must also reflect this change. This modern approach to health and illness is actually a reconciliation of the two disciplines that were previously viewed as independent of one another. Nettleton (1995) observes that 'medicine has come to acknowledge the thinking person who resides within a social context, and sociology has come to accept the physical as well as the lived body as central to its study' (p. 12). Linking these two disciplines can provide sociologists with a more comprehensive understanding of the illness experience. This chapter discusses theoretical approaches that are applicable to the study of Saudi women with ESRF.

A shift in the nature of disease

Medical sociologists have pointed out that medical advancements of the 20th century have brought many challenges to the various fields of medicine and healthcare. The major challenge that has had the most impact on society and can be directly attributed to these medical advancements is prolonging the length of life. Ironically, with the increase in the life expectancy of individuals, has come an increase in diseases that were once fatal, but are now chronic due to the assistance of sophisticated medical procedures, innovative technology and vital pharmacological discoveries. Today, people are living longer lives; yet they are experiencing greater hardships due to long-term illnesses. These hardships or 'diseased burdens', as labelled by Nettleton (1995), stem from the sufferer's prolonged need for continuous monitoring and care (p. 11). Taylor and Field (1997) agree that modern societies have 'shifted very markedly from the acute infectious diseases characteristic of the nineteenth and early twentieth centuries to long term, chronic diseases' (p. 128), which are characterized as being long-term, recurrent, indefinite, progressive and incurable. These characteristics suggest that the life of the afflicted individual is significantly disrupted and that he or she may face not only a medical and physical dilemma, but a psychological (depression, despair), social (inter-personal), and an
A comprehensive definition of the term chronic disease includes: 'All impairments or deviation from normal [and] are permanent, leave residual disability, are caused by non-reversible pathological alteration, require special training of the patient for rehabilitation, and may be expected to require a long period of supervision, observation, or care' (Mayo, 1956, as quoted in Lubkin and Larsin, 2002: 8). Some of these diseases include diabetes, heart disease, renal disease, lung disease, chronic respiratory disorder, multiple sclerosis, cancer, thalassemia, Crohn’s syndrome, Parkinson’s, Alzheimer’s, Lou Gerhigs disease, and many others.

In the light of this shift in the nature of disease from acute to chronic, sociologists recognize that a comparable shift in the healthcare system to address the unique issues relevant to chronic illness is required. At the present, the healthcare system is still designed and operated primarily to provide services for acute care although most health problems are chronic (Thorne, 1993: 9). Due to these significant differences in the nature of chronic illness, Nettleton (1995: 12) notes a trend towards a new paradigm of healthcare that focuses on chronic illness by replacing intervention with monitoring, treatment with care and cure with prevention.

A shift in understanding chronic illness

In addition to the shifts in the nature of disease and the healthcare system, there also needs to be a shift in understanding and defining the illness experience from a medical perspective to a sociological one. The medical perspective to understanding illness is confined to the practitioner's medical assumptions and does not include the lived experience of the sufferer. This medical approach dictates that the practitioner focuses on the biophysical aspects of the disease and therefore the patient's social and economic concerns are not considered in the medical treatment. The practitioner's reluctance to recognize the patient as an active participant rather than just as an object of investigation and cure, results in a lack of communication that may become a barrier in the practitioner-patient relationship. This conflict between the practitioner's assumptions and the patient's experience is noted in studies that show how a practitioner's feelings may range from insensitivity to a reluctance of accepting 'cooperative models of healthcare' (Thorne, 1993: 8). This attitude is 'culturally embedded' and 'has been described as the source of numerous systematic errors in medical practice...' (p. 8).

Within the literature on sociology of health and illness, a distinction is made between the concepts of disease and illness. Sociologists consider the medical term 'disease' as restrictive when studying how a sufferer experiences illness. According to Radley (1994), 'disease' is the term used by medical practitioners to describe a diagnosis of pathological changes (symptoms) in the body that requires treatment. Thus, sociologists define the term 'illness' to embrace the sufferer's whole experience with the disease including biophysical changes, emotional feelings relating to bodily changes, and the socio-psychological and economic impact the disease has on the sufferer's life. Radley asserts that 'illness, therefore, relates to a way of being for the individual concerned' (p. 3). Due to the nature of chronic illness, the sufferer struggles with both the disease and the experience that changes or disrupts his or her life on a daily basis. Such afflicted individuals are forced to alter and adjust their way of life. In light of this, Nettleton (1995), acknowledges that 'biophysical changes have significant social consequences' and 'illness reminds
us that the 'normal' functioning of our minds and bodies is central to social action and interaction' (p. 69).

Since terminology can strongly influence the approach taken by medical practitioners and sociologists when they interpret the chronic illness experience, Conrad (1990), asserts that in order for researchers to gain a more comprehensive insight into the illness experience, they have to view a chronically ill person as a 'sufferer' rather than a 'patient'. Then the sufferer is not merely perceived in the role of patient within a medical setting; but as having other roles and interactions, such as those associated with their home, work and other settings. Thus, in order to comprehend how chronic illness alters a sufferer's roles and interactions, the sufferer's 'subjective experience' must be considered in studies examining the chronic illness experience: 'Such a perspective necessarily focuses on the meaning of illness, the social organization of the sufferer's world, and the strategies used in adaptation' (p. 1260). It can therefore be inferred from Conrad that chronic illness must also be considered in terms of how society defines the illness experience. Falvo (1999), also points out that 'handicapping depends to a great extent on the individual’s ... environment; and the reactions of family, friends, and society in general' (p. 17). Thus, sociologists must not ignore the sufferers' social background when attempting to understand their illness experience.

Theoretical approaches to chronic illness

The sociological paradigm of chronic illness can be examined in light of two approaches: structural and interactionist. Clarke (2001) explains that the structural approach is a 'macro-level' approach that assumes that the various structures of society are 'largely responsible for determining and shaping patterns of human behaviour' (p. 14); or specific to my study, have an impact on the life of Saudi women with ESRF. The structuralist assumes that society is a 'relatively stable system - and [that] people within it [are] products of that system' (Kelly and Field, 1998: 5). In order to understand an individual's behaviour, the researcher 'focuses on the ways in which social life is organized and social order achieved' (Clarke, 2001: 8); and identifies the particular structure that influences that behaviour. This approach includes examining illness from the perspective that illness causes a breakdown in the social system by preventing individuals from fulfilling their social responsibilities as defined by their society (p. 8).

The structural approach can be sub-divided into structural and political economy. Structural theorists view society as a 'harmonious and stable set of interlinked social roles and structures' (White, 2002: 7). Within this framework, illness is considered and treated as a disruptive factor in the sufferer's life. However, it is recognized that this biological condition extends beyond the sufferer's body, affecting the structural and functional aspects of the social system. Thus, under this approach, the role of the medical profession can be seen to control the sick and maintain social harmony.

The political economy approach differs from structural in that it focuses on political-economic factors rather than social ones. In other words, the capitalist system, a western industrial economy, is held to account for the 'production' of illness and the ways in which healthcare is managed and delivered (Kelly and Field, 1998: 4).
In contrast to structural and political economy, the interactionist approach examines illness from the sufferer's perspective or at the 'micro-level' where individuals are characterized as 'actors' who engage in social action with other people; and all social action is viewed as 'meaningful' action that must be examined (Clarke, 2001: 14). This approach is not limited to how illness affects the social system or how the social system impacts on ill individuals; rather, it is concerned with how individuals 'attribute meaning to their own actions [and] also interpret the actions of other people' (p. 14) in order to construct the meaning of their illness experience.

**Structural approach**

In relation to the structural perspective, Parsons (1951, as quoted in Annandale, 1998: 10) does not emphasize illness from a sick person's viewpoint, but analyses illness in terms of its impact on the social system. His 'sick role' theory focuses on the social nature of illness where illness is 'a social phenomenon rather than a physical property of individuals' (Clarke, 2001: 9). Parsons' theory regards ill health 'as the inability to fulfil valued social roles' (p. 10). This extended the term 'sick' to the physically and mentally or psychologically stressed and challenged individual. More specifically Parsons' sick role theory embodied four defining features or characteristics of a sick person. Each of these would have to be accepted by a given individual to show that they had taken on the 'sick role'. The individual would have to understand that, firstly, he is unable to fulfil social roles, and secondly that he is 'not responsible for his condition and cannot cure himself' (Schwartz and Kart, 1978: 2). Thirdly, the individual must also acknowledge that his condition is not desirable and that he needs to get well and therefore, lastly seek professional help (Ritzer, 2003: 79). This was also seen to comprise two rights and two obligations. The rights were seen as the allowance to be excused from 'normal social roles and blame for ill health' (Annandale, 1998: 10), whereas the obligations were seen as getting well and seeking professional help.

However, Parsons' theory overlooks many aspects of the experience of the ill. This may well be because he was interested in 'how the system controls the actor [sufferer] not how the actor [sufferer] creates and maintains the system' (Ritzer, 2003: 86). Parsons' theory is criticized for its rigid functionalist basis in which a sick person is seen as a deviant who is 'permitted to break the rules, but only if the obligations (which are functional for society) are met' (Bowling, 2002: 30). Similarly, it is criticized for its lack of flexibility to include patients who are generally sick, such as with flu, or women with menstrual pain, but do not wish to seek help. Such patients are not seen to fulfil their obligations as a 'sick' person and thus their situation is disregarded by Parsons' theory. Parsons' theory is therefore limited and needs to be modified to include illnesses that do not require a physician's consultation in order for the patient to get well.

Another more recent criticism which is relevant to this thesis is the relative inability of Parsons' theory to account for and relate to chronic illness by assuming that the sufferer will eventually get well and that 'the patient would willingly comply with the physician' (Annandale, 1998: 11). These assumptions deny the very nature of chronic illness: long-term and permanent. It is only in cases of acute illness where treatment is undisputed and the patient must submit to the physician's authority, such as 'an acutely inflamed appendix or... [an] accident victim with a badly broken
leg' (Mumford, 1983: 42), does the patient's condition return to normal so that he is able to fully resume his responsibilities. However, in cases of chronic illness, the patient shares the responsibility of treatment with the physician by being directly involved in the control of diet and exercise and does not necessarily consult the doctor on these issues. Instead, the sufferer may vary diet and exercise on any given day according to his or her state of well-being. In view of this aspect of chronic illness, the sick role theory would need to be adjusted to acknowledge the patient's perspective as well.

**Political-economy approach**

The second structural approach is the political-economy approach of ill health, which attempts to explain how a political and economic structure, such as capitalism, affects health and healthcare. This approach recognizes that production of goods, hazards in the workplace, etc. result in the 'social production of ill health under capitalism' (Annandale, 1998: 12). Health and illness is therefore analysed within a structural framework that ignores the subjective reality that an individual and his/her personal choices may influence his/her health condition. This approach also recognizes the relationship between the capitalist system and the medical field, where the medical professionals may act as agents of social control (Clarke, 2001: 13). In a capitalist economy, there is a direct conflict between healthcare delivery and making profit. Thus, this structuralist approach argues that disease cannot be eliminated by medical science alone, but by a change in the political-economic system.

A weakness inherent in the structural approach in relation to chronic illness is that both structural and political economy regard medicine as an institution that defines the sick role and controls how healthcare is delivered to the sick. Both approaches ignore that the ill person is an active participant who is directly involved with the illness and treatment; and that illness has an impact on family roles and relationships.

**Interactionist approach**

Unlike the socio-structural approach, interactionism focuses on the sufferer's experience with their illness. Although there is a biological basis for the illness experience, this approach recognizes that an individual's self is the 'social product' arising out of roles and relationships with others and that the sufferer's self alters with these kinds of interaction (Annandale, 1998: 21). Thus, routine activities and social interactions of the sufferer are examined. While the structuralists assume that illness is a negative experience, the interactionists acknowledge that experiences of the sufferer can be positive as well (Kelly and Field, 1998: 6) and places more emphasis on the sufferer's meaning of that particular experience.

As an interactionist, Charmaz (1983) also presumes that the self is naturally social and therefore is formed through social relations. She recognizes that roles and relationships drastically change as the sufferer no longer performs activities in the same way that the former self was once able to do. Using the interactionist approach, she analyses how new self-concepts are defined as old ones are resigned by the chronically ill during their life. Since experiences and meanings that previously shaped an individual's self-image become absent following the onset of
chronic illness, Charmaz characterizes this illness experience as the 'loss of self' which she asserts is a 'fundamental form of suffering' (p. 168) that results in a diminished self-concept.

Not only does the sufferer’s self-concept change with the loss of self; but the sufferer’s expectations and performance of daily activities must also change to accommodate the limitations imposed by the illness. The sufferer's interactions with self and with others; performance of responsibilities; and responses to chronic illness and medical regimen must be 'negotiated' to adjust to a changed reality, an altered self, and identity. Bury (1997) discerns that the changing condition of illness from one that is acute to chronic in nature requires sufferers to negotiate all aspects of their everyday life when attempting to manage the long-term effects of their illness. In fact, the interactionist approach considers 'negotiation' as a key concept that sharply contrasts with structuralism (pp. 7-8).

On the other hand, Day and Day (1977: 134) criticize the interactionist approach for discounting the 'realities of power and politics' and argue that interactionism pays little attention to the ways in which a sufferer’s struggle with illness is determined and shaped by the 'larger structural features of society' (as quoted in Annandale, 1998: 29). Day and Day denounce this approach as a failure to recognize that certain negotiations a sufferer employs to normalize his or her life are beyond any individual's control.

Post-modernist approach

Unlike the theoretical approaches discussed above, Annandale (1998) asserts that 'post-modernism is not a unitary body of thought' (p. 45). This approach is difficult to succinctly outline due to what the theory itself represents: 'heterogeneity, multiplicity, and difference' (Flax, 1990a: 188, as quoted in Annandale, 1998: 45). The aim of post-modernists is to understand the world by acknowledging its nature of plurality, rather than using the modernist perspective of the world that is grounded in 'binary logic' or 'dualisms' (Annandale, 1998: 46). An example of this modernist view is found in the field of health and illness where the duality of 'able-bodied/disabled' is used to understand the illness experience. When characterizing reality, post-modernists reject this type of binary logic because they believe it overlooks the various causes and effects that are a part of reality. It is through this rejection that post-modernism 'aims to deconstruct the dualities of modernist thought and to reveal them as artefacts of a particular way of knowing the world' (p. 46). Thus, in the field of health and illness, the deconstruction approach rejects 'able-bodied/disabled' as a label to describe the reality of an ill person. Annandale comments that few sociologists actually apply this approach to the field of health and illness and notes that the sociology of health and illness still maintains the traditional modernist perspective of the world 'built around duality' (pp. 46-7).

In contrast to the structural approach where the structure of society is emphasized at the expense of the individual, post-modernism stresses the importance of the individual prerogative in making life choices and taking risks. Kelly and Field (1998) note that prior to the post-modern approach, society was regarded as a rational world where progress developed out of the order imposed upon it by a structured society (p. 9). However, the post-modern view in response to modernism rejects rigid order and absolute truths. White (2002) defines post-modernism as the
'changes in capitalist society over the past thirty years' (p. 54) that is 'reflected in the various political and economic structures of modern societies' (p. 53), e.g. decline of the industrial sector, unionization and the working class; relaxation of boundaries between public and private sectors, class and gender status (p. 54).

Kelly and Field (1998) also assert that the above-mentioned shifts in social structures have had an impact on health and illness in society, in particular, chronic illness (p. 10). They argue how the identity of being chronically ill must be explored differently in a post-modern society where identity no longer reflects the social structure of modern society, in other words, core identities of work, family, etc. (p. 14). As 'fragmentation of institutions and reshaping of social forms' (p. 11) in post-modern society reshape these core identities, the identity of being chronically ill is also altered.

Kelly and Field (1998) make a cogent argument that the identity of chronically ill individuals should be examined against the backdrop of these post-modern socio-structural changes. They note how post-modernism has changed the prevalent view in traditional modern literature such as Goffman (1963), who asserts that the spoiled appearance of a chronically ill person negatively affects his or her identity and self-concept. However, in post-modernism there is a change in perspective where difference in appearance is no longer considered negatively, leading 'not only to a kind of relativism in the aesthetics of appearance but also to a demand for tolerance of difference' (Kelly and Field, 1998: 15). This post-modern perspective may have a positive effect on how society views the chronically ill, and also on how the chronically ill are able to accept the changes in their appearance.

Another important impact post-modernism may have on the identity and self-concept of the chronically ill is the 'increasing challenge to the hegemony of medicine' (Kelly and Field, 1998: 16). Originally, the sick role in chronic illness was solely defined by the medical profession. Now, the concept is defined by a variety of sources, e.g. alternative medicine and the mass media, where people can learn about health and illness from both experts and patients. The chronic illness experience is televised in dramas and described in magazines and over the Internet. This public exposure has 'normalised' chronic illness for society as well as the sufferer (p. 16). This is one of the key characteristics of post-modernism that Nettleton (1995) refers to as a 'breakdown of hierarchies of knowledge' (p. 34) which blurs the distinction that is usually made between medical experts and laymen and validates all knowledge regardless of the source.

The post-modernist's approach has its drawbacks despite its focus on relieving the individual from a rigid structural reality. As ideal as it may sound that post-modernism encourages individuals to choose their own lifestyle and pursue their own interests without the confinement of various structures of society, the reality of this approach is less than ideal. White (2002) argues that the post-modern economic changes in society have a significant effect on disease and how it is managed. Sociologists have noticed that these economic and socio-political changes mark a turn away from a centralized state that previously provided either free or subsidized medical services to the public and a turn towards the view that individuals are responsible for their own healthcare (p. 53). Since an individual's healthcare increasingly depends on his or her financial means, accessibility of healthcare services may be severely limited.
Studies and models of chronic illness

The central approach utilized in my study to explore the illness experience of Saudi women afflicted with ESRF is influenced by interactionism. This section discusses studies and models in the field of health and illness that have been applied by interactionists when exploring the impact of chronic illness on individuals. The development of sociological concepts regarding the illness experience of the individual is also explored.

Bury (1982) coined the term 'biographical disruption' when describing the experience of chronic illness for the individual. He asserts that approaching chronic illness as a 'disruptive event' (p. 168) in the life of an ill person allows sociologists to examine how practical management and social relationships are altered by the onset of symptoms. Bury distinguishes two types of 'meaning' when examining the various effects chronic illness has on the life of an ill person: meaning of 'consequences' and meaning of 'significance' (Bury, 1991: 453; Bury 1997: 124). The meaning of 'consequences' involves the disruptive effects the illness has on the individual's daily activities, which include regimen management. The meaning of 'significance' involves the individual's sense of self at the onset of symptoms of the illness. This new identity reflects both the individual's concept of self as a chronically ill person in relationship to others; and society's definition and attitude towards the chronically ill as it is influenced by cultural norms. This type of meaning can prove to be more disruptive to the ill person's life than the disabling effects of the disease itself.

Charmaz (1983), like Bury, concerns her study with the disruptive nature of chronic illness on the individual's life. She contends that a crucial part of the nature of suffering for the chronically ill is the 'loss of self' brought about by 'spiralling consequences' of chronic illness: leading restricted lives; experiencing social isolation; being discredited; financial crisis and family strain (Charmaz, 1983: 168-9). These 'spiralling consequences' accumulate over time and eventually erode the chronically ill person's original self-images. She asserts that if former self-images are not replaced by new ones, the result is a diminished self-concept and subsequently a 'loss of self'.

To further understand how chronically ill individuals account for the causes of the disruption in their life and ultimately make sense of their illness, Williams (1984) asserts that their beliefs about how and why they became ill must be examined 'as part of the larger interpretive process'; which he refers to as 'narrative reconstruction' (p. 177). When studying cases of chronically ill people, he found that they attempted through the use of narratives, to 'reconstruct a sense of order from the fragmentation produced by chronic illness' by 'establish[ing] points of reference between body, self, and society...' (p. 177). Radley (1994) observes that narrative reconstruction can also serve the purpose of repairing the disruptions (which Charmaz refers to as 'spiralling consequences'); and further aids the individual in figuring out a way to live with others as an ill person (p. 146).

Radley and Green (1987) discuss a conceptual model that divides the individual's adjustment to chronic illness into four modes: accommodation, active denial, secondary gain, and resignation. They place these four modes of adjustment within
a two-dimensional framework (p. 182). Radley and Green have purposely used the word 'mode' to 'signify a coordination of bodily feeling and social action together' (p. 184). The first dimension (on the horizontal axis) represents the relationship between the individual and society and the way roles and responsibilities are maintained (social participation retained or lost). The second dimension (on the vertical axis) represents the relationship between the individual's self and how the individual copes with the condition (self complimentary or opposed to illness) (p. 183). This dimension distinguishes between the different attitudes the ill person has towards the condition by either accepting or rejecting it (Radley, 1994: 153). In short, this conceptual model depicts an individual's 'need to resolve the competing demands of bodily symptoms and those of society' (p. 152). The individual's 'style of adjustment' (p. 154) is his or her use of one or more of these modes to reconcile these competing demands.

Kelly and Field's (1996) approach to the study of chronic illness accepts both the biological and sociological facets of chronic illness. They integrate these two approaches of study by understanding that as the body changes with chronic illness, so do the sociological concepts of self and identity of the sufferer. The illness can affect the body in many ways, e.g. through pain, physical limitations, etc. These body changes then go on to affect the sufferer's way of seeing his or herself with respect to their ability to perform responsibilities (self-concept) and also affect the way other people perceive and define (identity) the sufferer (p. 247). Thus, there is a relationship between the biological and social facets of chronic illness. The physical symptoms not only have physical consequences for the individual, but also have social consequences that can be analysed using concepts such as self and identity. In essence, 'biological facts become social facts' (p. 252) because society responds to the sufferer in relation to his or her physical condition.

Conclusion

Modern medical and technological advancements have impacted on the nature of disease and how it is treated. Now that length of life is extended and the nature of disease has shifted from acute to chronic, the physicians and sociologists share common concerns where treatment must now include long-term care. Permanence and residual disability which define chronic disease shift the burden of care from health practitioners to family and community. This transformation requires a new policy in healthcare management that takes into account the social ramifications of disease and treatment.

Literature in the field of medical sociology reveals the shift in theoretical approaches as well as in sociological concepts and models applied to the study of health and disease. This shift is the result of sociologists recognizing that health and disease can no longer be treated as purely a biomedical problem that solely lies with the realm of physicians; but is also related to the ill person's social circumstances. The movement from the traditional medico-centric perspective to a sociological one leads to a more comprehensive understanding of the illness experience which has evolved into the sociology of health and illness. This approach takes into account both sociological as well as biological factors that affect the illness experience and examines all aspects of a chronically ill person's life. Thus, the original dichotomy between the medical and sociological views converges, and their mutual focal point
is the body. However, the concept of the body is no longer treated merely as an anatomical entity with only biomedical relevance, but as a part of a whole experience that involves interpretation and social importance.

Sociologists now concentrate on studying the impact chronic illness has on the ill person's quality of life, as well as that of society. They recognize that their understanding of the illness experience depends on examining how the individual adjusts to the 'disruptive event' which involves how practical management of daily life and social relationships are altered. Since disruptions have 'spiralling consequences' that alter the ill person's self-concept and can eventually lead to a 'loss of self', he or she must interpret these disruptions in order to make sense of the illness and adjust to a new way of life.

In order to examine the whole illness experience of Saudi women with ESRF, which includes their bodily changes, as well as their socio-psychological and economic aspects of life, the interactionist approach must be implemented to explore the various effects chronic illness has on their life. Both the meanings of 'consequences' and the meanings of 'significance' should be interpreted from their narratives in order to understand how both the disease and the experience disrupts their routine activities and social interactions which may result in a diminished self-concept and identity.
Chapter Three
Approaches to Defining Disability

This chapter explores the different perspectives that underlie the models of western disability studies; examines the contemporary disability movement's influence in redefining disability; and discusses the approaches to understanding to what extent disabled people have a 'disability identity'. Disability identity is analysed from the perspective of both disability theorists and disabled people; and a critical evaluation is made concerning western definitions of disability, impairment and disability identity that is relevant to examining later whether Saudi women with ESRF are disabled.

Establishing a perspective

A traditional perspective has dominated the understanding of disability in medical literature and influenced the approach taken by medical sociologists when analyzing the impact of disability on the individual. This views disability as an 'individual problem caused by impairment' and simplifies it as the 'inevitable result of individual differences or biology' (Priestley, 2003: 12). With this perspective, comes the assumption that the disabled individual is either incapable of or finds difficulty in performing normal activities and fulfilling roles expected by society; and therefore needs help in adjusting to and accepting a 'less valued' way of life (p. 12).

In contrast to the traditional perspective of disability, the contemporary perspective does not assume that there is a causal relationship between impairment and disability. Due to the disabled people's movement, there has been a shift in focus from the individual to the social. Instead, differences in disability experiences are recognized because varied social circumstances amongst disabled people are acknowledged. Priestley (2003) infers that 'the disadvantage often associated with disability might be a social rather than an individual phenomenon, something that is not biologically determined but produced by particular social processes' (p. 13). In other words, disability can be considered as the result of society's failure to recognize the differences amongst its members and meet their various needs.

There is an ongoing debate between the medical sociologists and disability theorists in defining disability as well as in choosing the most relevant sociological model to use when studying disability. Barnes et al. (1999: 40) comment on how disability theorists are influenced by the structural approach; whereas, sociologists studying chronic illness more often use an interactionist approach. It can be determined from the literature that the reason disability theorists prefer the structural approach is that they define disability as a socio-political problem whereby societal structures are the disabler. Moreover, they criticize interactionists for concentrating on personal experiences of the disabled and confining their definition of disability to the personal problem of the individual sufferer whose disability is caused by functional losses.

Defining disability and selecting a relevant model

The opposing perspectives held by medical sociologists and disability theorists underlie their theoretical approaches and have led to the development of two distinct
models of disability. When discussing disability models, Swain et al. (2003) focus on the primary distinction between the medical and social models. In the medical model (also known as the individual model), disability is narrowly defined as a physical characteristic or functional limitations of the individual body, placing the responsibility for treatment within the control of the medical profession; whereas the social model defines disability as a social and political process (pp. 22-3), placing the responsibility on society as well as the disabled individual.

Disabled people's organizations have criticized the medical model of disability and redefined it according to their reality, e.g., the Union of the Physically Impaired Against Segregation (UPIAS) described their viewpoint:

'In our view it is society which disables physically impaired people. Disability is something imposed on top of our impairments by the way we are unnecessarily isolated and excluded from full participation in society. Disabled people are therefore an oppressed group in society' (UPIAS, 1976: 14, cited in Oliver, 1996: 33).

In response to the disabled people's criticism against the sole use of the medical model, the World Health Organization (WHO) produced its International Classification of Impairments, Disabilities and Handicaps (ICIDH) which still defined disability from the medical perspective as 'a restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being'; but added the term 'handicap' defined as:

'A disadvantage for a given individual, resulting from an impairment or disability that limits or prevents the fulfilment of a role (depending on age, sex, social and cultural factors) for that individual' (WHO, 1980: 29, cited in Barnes and Mercer, 2003: 13).

This definition provoked further criticism from supporters of the social model of disability who perceived it as just another version of the medical model 'because it sets up a chain of causation wherein impairment causes disability (Impairment → Disability). Handicap is seen to flow, in turn, from disability (Impairment → Disability → Handicap)' (Thomas, 1999: 33). The addition of the term handicap in the ICIDH schema is seen by the critics as WHO's compromise in attempting to address the social aspects that are overlooked in their definition of disability. In fact, Oliver (1996: 34), a disability theorist, claims that the WHO's definition of 'handicap' is the same as the UPIAS definition of disability. However, Thomas points out that medical sociologists view this schema as a break with the medical model in that disability is no longer equivalent to impairment (Disability = Impairment), rather it is viewed as a consequence of the impairment that affects daily activities and social interaction (Impairment → Disability). 'Thus, the ICIDH is seen as representing an important step forward because it considers the individual in social context' (Thomas, 1999: 148).

Bury (1997), a medical sociologist, accepts the ICIDH schema as an attempt to explain unclear terminology by providing more consistent definitions; and uses it in his research on chronic illness and disability (p. 118). In contrast, the organizations for disabled people criticize the schema for relying on medical terms; and ignoring
the varied social and cultural expectations that different societies have with respect to the roles of its members. They argue that under ICIDH's definition of 'handicap', a person may be deemed disabled yet not handicapped based on the restrictions placed on the person by society, e.g., in societies where activities are restricted according to gender, a woman can be disabled but not considered handicapped because she is not expected to perform the restricted activities (Barnes and Mercer, 2003: 14).

Another criticism that organizations for disabled people have against the ICIDH's schema is that by identifying impairment as the cause of disability and handicap, the health profession seems justified in dominating the treatment and services for disabled people. Since the schema relies on the medical model, the ICIDH also focuses on the diagnosis and treatment of the impairment, rather than examining the social, economic and cultural barriers that lead to the social exclusion of a disabled person that ultimately causes the disability or handicap (Barnes and Mercer, 2003: 15).

In response to disapproval from organizations for disabled people and disability theorists, WHO (1999) amended the ICIDH schema (popularly known as ICIDH-2) to 'replace 'disability' with activities and 'handicap' with participation'; yet 'retain the concept of impairment in body function and structure'. The intention was to 'incorporate the 'medical' and 'social' models into a 'biopsychosocial' approach' (Barnes and Mercer, 2003: 15). Although the amendment maintains the individualistic medical approach of disability, it is seen by some medical sociologists, such as Bury, to embrace a 'socio-medical model of disabling illness' (1997: 116) that acknowledges the impact of environmental factors on body function, activity and participation (Barnes and Mercer, 2003: 15).

In 1983, Oliver (1996), influenced by the original definition of disability by the UPIAS, 'conceptualized disability models as the binary distinction between what [he] chose to call the individual and social models of disability' (p. 30). In this distinction, he rejects the medical model (or what he terms as the 'individual model') for its basic premise. He refers to the basic premise as the personal tragedy theory of disability 'which suggests that disability is some terrible chance event which occurs at random to unfortunate individuals' (p. 31). Instead, he asserts that disability is a social problem caused by a society that fails to provide appropriate services for disabled persons e.g., from inaccessible public buildings and unusable transport systems to segregated educational facilities. Unlike the individual model of disability, his 'social model' shifts the responsibility away from the disabled person on to a society that imposes socio-structural barriers on them. Thus, Oliver's social model views disability as a systematic form of prejudice that oppresses the disabled and excludes them from the mainstream of society (pp. 32-3). Swain et al. (2003) also recognize the importance of the social model of disability for providing 'an alternative understanding of the experience and reality of disability, it has given disabled people a basis on which to organize themselves collectively' (p. 24).

Similar to other disability theorists, Crow (1996), cited in Swain et al, 2003: 25), acknowledges the significance and popular acceptance of Oliver's (1996) social model, but argues that its complete focus on the structural cause for disability excludes the impact impairment has on the lives of the disabled. She points out the need for a 'renewed social model of disability' that will allow for a more
comprehensive understanding of disability (p. 25). As sociologists who study chronic illness eventually incorporate the bio-medical aspect of the disease as part of their study of the sufferer's illness experience; Crow asserts that disability theorists must address both the nature of impairment and disability that would recognize the disabled individual's personal experiences as well as their public experiences. Since this comprehensive perspective on disability allows the disability theorists to broaden their study to include the disabled individual's personal experience, the relevance of utilizing narrative reconstruction, which has been a bone of contention amongst the structuralists, can no longer be considered to weaken the case of the disabled individual (Swain et al., 2003: 25).

In addition to incorporating 'the sociology of impairment into the social model of disability' and considering 'the individual experiences of disabled people in order to develop a broader account' (Swain et al., 2003: 36) in disability studies, there is a trend to expand the original definition of impairment to also include functional limitation caused by 'mental or sensory impairment' (DPI, 1982, cited in Thomas, 1999: 15). Thomas (1999: 46-7) further broadens the definition of disability to 'go beyond doing'. She argues that disability theorists should not only focus their concern on what the disabled 'can do', but should also be concerned with how the disabled 'feel and think' about themselves. Thus, she suggests that the social model of disability should be broadened to include the 'psycho-emotional dimensions' of disability, since social barriers not only place restrictions on activity, but also pose limitations on the psycho-emotional well-being of the disabled person. Concurring with Thomas, Reeve (2002) points out that recognizing both the impairment and disability of disabled persons 'is politically unifying rather than divisive because it enables recognition of the range of disability experiences' (p. 504). She further acknowledges that 'a social model of disability which includes both structural and psycho-emotional dimensions of disability' can benefit the disabled people's movement (p. 504).

The varied definitions of disability cannot be considered a capricious debate amongst medical sociologists, disability theorists and organizations for disabled people. Aside from the importance it has for sociological research, how disability is defined goes right to the heart of the disabled people's movement. Disabled people, in their attempts to challenge stereotypical images and roles placed upon them by society, decided to 'reclaim language' to redefine themselves; which 'became part of the process by which the movement defined itself' (Hasler, 1993: 281). What Hasler refers to as the 'terminology debate' (p. 282) is not just a way for disabled people to relate their experience to society, but more importantly, it is a way to shape policy that affects their way of life. Understanding the power of language and how it can effectively change conditions for the disabled, Wendell (1996) connects the definitions of disability with social policy: 'Definitions of disability officially accepted by government bureaucracies and social service agencies determine people's legal and practical entitlement to many forms of assistance...' (pp. 11-12, quoted in Thomas, 1999: 36). Furthermore, Thomas (1996) asserts that it is these official definitions which lend credence to specific social meanings that influence roles and legislation. She further contends that disabled people suffer the consequences when they are excluded from such definitions. It is for these reasons that disability advocates continue to refine and expand definitions of disability to include all aspects of the disability experience.
Disability identity

Shakespeare (1996, cited in, Watson, 2002: 513) explains that the significance of defining disability identity is that it allows us to understand the multi-faceted relationship between disabled individuals, biology and society. He recognizes that the nature of identity and the process of identity formation have caused contention between disability theorists and other social scientists. Various ideologies throughout the 20th century influenced sociological approaches employed in analyzing identity formation. In their summary about the emergence of theories of identity, Riddell and Watson (2003: 10) comment that the structuralist approach influenced by political-economy theory that defined the individual's identity as a product of a person's economic class was expanded by Oliver (1990) to illustrate how disabled people were also oppressed by society which depicted them as being less than normal. Negative ideologies that affect society's perspective about the disabled also affect the expectations of disabled people. They limit themselves and their social and political possibilities when a negative disability identity is imposed upon them by society. Influenced by the socio-political movements of the 60s, 'the disability movement, emerging during the 1970s and 80s, took on the task of raising political consciousness so that these limiting ideologies could be challenged and disabled people could develop a far more positive identity' (Riddell and Watson, 2003: 10).

It is recognized by some sociologists that society is undergoing increasingly rapid changes during this post-modern era, which make it difficult for people to retain a single, unified identity. Theories of identity are therefore challenged by 'post-structuralists' (Riddell and Watson, 2003) who believe that people now possess a 'fragmented' identity consisting of several identities that may be in conflict with one another (Hall, 1992, cited in Haralambos and Holborn, 2000: 923). Claiming that identity is no longer fixed, Riddell and Watson (2003) describe individuals as constantly 'negotiating identity' (p. 10) to adjust themselves to challenges they confront on a daily basis. Disabled people are now choosing their own identity by either responding to or ignoring what society tries to impose on them. They do not necessarily identify themselves with other disabled people; but recognize their individuality. The political ramifications of no longer accepting a fixed or stable identity are discussed later in this chapter.

Approaches to understanding identity

Literature on chronic illness and disability regarding identity issues examines identity formation from various theoretical orientations: biological roots, social constructs or individual experience (Woodward, 1997: 24). The literature on identity issues specifically examines how disabled people identify themselves: whether they identify themselves according to their impairment (biological); whether they view themselves as oppressed people who are discriminated against (social); or whether they define their identity based on who they think they are (individual) (Watson, 2002: 512).

Hall (1996, cited in Watson, 2002: 509) identifies two theoretical approaches that social scientists employ to understand identity, which have also influenced disability theorists: the 'essentialist' approach and 'constructionist' approach.
Watson (2002) points out that the essentialist approach is based on the assumption 'that there is an essential, natural or intrinsic meaning to any identity' which is then shaped by 'a shared social experience, origin or structure' (p. 509). Furthermore, essentialists believe that the natural or original essence which comprises a particular person or thing falls outside the social order. This natural essence then provides the starting point for social customs and structures. Thomas, (1999) therefore asserts that essential differences come before socially constructed differences (pp. 103-4). Thomas refers to this essentialist approach as a 'categorical' one which identifies an individual by the categories that describe his or her intrinsic difference (p. 113); and according to this approach, the impaired body is an essential difference.

In contrast, constructionists 'are concerned above all with the production and organization of differences, and they therefore reject the idea that any essential or natural givens precede the processes of social determination' (Fuss, 1989: 3). The main premise of the constructionist approach is that 'the body is socially constructed or created' and an individual's identity 'depends on the social, cultural and historical context' of the individual (Greenwell, 2003: 99). Fuss sums up these two diametrically opposed approaches: '...while the essentialist holds that the natural is repressed by the social, the constructionist maintains that the natural is produced by the social' (1989: 3). Yet, as will be discussed below, both approaches can be considered when identifying the various factors that form identity.

**Identity formation based on difference**

It should be noted that although the essentialist and constructionist approaches are fundamentally incompatible, Fuss (1989) argues that 'social constructionists do not definitively escape the pull of essentialism, that indeed essentialism subtends the very ideal of constructionism' (p. 5). Thomas (1999) illustrates how these approaches are conflated by two feminists writers, Morris (1991) and Wendell (1996), regarding issues on women, disability identity and difference. All of these writers begin with an essentialist premise by asserting that the essential underlying difference (impairment-related) between disabled and non-disabled people exists prior to social differences. Thomas (1999) also acknowledges that attached to the biological entity (impaired person) are socially constructed differences (p. 104; p. 110).

Thomas (1999) comments on how Morris is 'very sensitive to difference' (p. 107) and attempts to 'read off' (p. 113) an identity from the categories to which an individual belongs, e.g., disabled, gender, race, etc. When Morris reads off the identity of a disabled person from these categories, she also recognizes that there are socially constructed differences that make one disability experience different from another, e.g., male disabled vs. female disabled. Yet, Thomas questions whether Morris goes far enough when discussing differences within the group of disabled women and perceives that Morris's analysis 'assumes too much sameness' (p. 109). Even though she recognizes Morris' work as politically significant for disabled women, she worries that disability identity will be defined in a rigid and fixed way by 'assuming commonalities and creating new shades of universalisms' that do not account for the many differences disabled women encompass (p. 109); resulting in what Watson (2002) refers to as the process of 'homogenization of disabled people in to a singular group'(p. 511).
Similar to Morris (1991), Thomas (1999) discerns an 'essential thread' in Wendell's 'emerging understanding of disability as socially constructed from biological differences [impairment] between the disabled and non-disabled' (Wendell, 1996: 5, cited in Thomas, 1999: 105). It is this 'interaction of the biological and the social to create (or prevent) disability' that Wendell calls 'the social construction of disability' (Wendell 1996: 35, cited in Thomas, 1999: 37). Thomas notes that although Wendell shares Morris' categorical approach by acknowledging that disabled people do share different experiences from able-bodied people; she is more circumspect about claiming 'false universalisms ...which constitute[s] the basis for a disabled identity' (Thomas, 1999: 113).

Wendell’s hesitation to declare that there is a universal identity amongst disabled people, raises a question concerning disability identity and difference which is crucial to her analysis: whether there can be a 'standpoint epistemology for people with disabilities' (Wendell, 1996: 69, cited in Thomas, 1999: 106). In other words, do disabled people have 'both knowledge and ways of knowing' that is exclusive to them and therefore inaccessible to non-disabled people? (p. 107). Although Wendell admits that all disabled people do not have the same 'standpoint' because they may have different interpretations of their experiences with disability based on other essential characteristics (gender, race, etc.); she also recognizes the importance in accepting and understanding that disabled people do have an epistemic advantage regarding certain issues concerning their disability that they share, such as, bodily suffering, physical limitations and how society treats them differently from able-bodied people (p. 107).

Consistent with Wendell's uncertainty about the existence of a universal disability identity, Barnes and Mercer (2003) contend that there is no justification for assuming that disabled people having an essential characteristic will also share similar experiences; and that any presumption of this kind 'attracts criticism that it is based on a false essentialism' (p. 77). Their position supports Wendell's argument that there is no single 'standpoint' that exists amongst the disabled population. In addition, Thomas (1999) suggests that employing a categorical approach to understanding disability identity has its pitfalls that inadvertently 'reinforce categories which have been socially produced within an oppressive disabilist and patriarchal society' (p. 113). Her criticism reflects a general concern that categorical classification of the disabled supports 'reductionist and ahistorical notions that there are fixed categories which produce fixed identities' (pp. 113-4). In other words, 'being disabled' is an immutable state of being that forms the same disability identity.

**Materialist perspective on identity**

Commenting on the literature on disability studies, Barnes et al (1999) note that, the perception of the body has changed. Disability theorists no longer confine impairment to a medical perspective, but recognize that the body is material: it has a history and experience that reveals that during the past it was medicalized and in the present it is part of a process of identity construction (p. 93). They conclude that 'a disabled body and identity do have a material reality' (p. 94).
In response to constructionist's rejection of all things being biological or socially reductionist, some disability theorists are examining theoretical alternatives that would include a 'non-reductionist materialist ontology of the body' (Thomas, 1999: 116). This materialist ontology suggests that identity is the product of interaction between one's 'real' body and the 'real' physical and social environments in which it exists; yet, is also a product of action taken by the individual. Thus, the formation of identity is neither 'passively constructed, nor 'read off' from particular categories; but rather 'both socially produced and self-constructed' (pp. 117-8).

Thomas refers to this theory of formation of identity as a 'bio-social interface' which allows disability theorists to recognize real biological differences among people whose material body has changed due to what has 'come to be culturally named and understood, through scientific medical discourses as impairments and abnormalities' (p. 116). She contends that this materialist perspective avoids the pitfalls of essentialism i.e., imposing a fixed biological identity on the disabled by assuming that there is a natural reason for impairment; as well as responds to issues that relativist deconstructionism fails to explain, e.g., the existence of binary divisions in society: disabled/non-disabled, impaired/non-impaired (p. 117).

**Narrative identity analysis**

Narrative analysis is widely used by sociologists in examining the formation of identity. Giddens (1991) holds the view that a narrative approach is relevant when he makes the connection between an individual's self-identity and biography by asserting that 'a person's identity is not to be found in behaviour, nor... in the reactions of others, but in the capacity to keep a particular narrative going' (p. 54). Based on this, individuals are said to be able to choose their own identity by creating their own narratives and reject identities foisted on them (Watson, 1994: 511): 'Self is thus a product of self-determination, autonomy, and choice' (p. 515).

Somers (1994: 606, cited in Barnes and Mercer, 2003: 79), asserts that utilizing a narrative approach avoids the rigidity of an essentialist framework for identity by introducing the 'categorically destabilizing dimensions of time, space, and relationality'. The dynamic nature of narratives enables a disabled person to discard a fixed identity which is ascribed by others; and actively create his or her own identity as experiences change and stories are being revised: '...it is through narrativity that we come to know, understand, and make sense of the world, and it is through narratives and narrativity that we constitute our social identities...' (p. 606).

Within a materialist perspective on identity, Thomas' (1999: 119-20) aligns herself with Giddens and Somers' approach that identity is narratively constructed and is 'something that has to be routinely created and sustained in the reflexive activities of the individual' (Giddens, 1991: 52). Thomas also agrees that 'social life is itself storied and that narrative is an ontological condition of social life... [and] that stories guide action...' (Somers, 1994: 613). From this, she asserts that the narrative approach enables social and political change within social movements, e.g., the disabled people's movement can effect change in the life of the disabled through 'counter-narratives' that ignore or reject identities attributed to them by dominant society; and construct new identities of their own.
Single/Shared or fragmented disability identity

Issues concerning identity in people who have an impairment or chronic condition are analysed differently in the field of medical sociology than in disability studies. Medical sociology literature particularly focuses on issues addressing adjustment to loss, coping and mourning. Interactionists, such as Goffman (1963) and Gerhardt (1989), examine how impaired individuals respond to their loss of self by negotiating their lives so that they will maintain some normalcy in order to manage their social interactions. However, in disability studies, identity and self are viewed from a structural approach in which society oppresses impaired individuals by obstructing social relations. Unlike medical sociology, the focus in these studies is to change society and empower the disabled (Watson, 2002: 513).

Oliver (1996) and other disability theorists who advocate a social model, define disability within fixed and rigid parameters that imply that disabled people possess a single/shared disability identity: '(i) the presence of an impairment; (ii) the experience of externally imposed restrictions; and (iii) self-identification as a disabled person' (p. 5). In recent years, literature reveals that disabled people themselves, along with other disability theorists, question the existence of such a single disability identity. Although Reeve (2002) recognizes the political convenience in adopting a concept of a single disability identity that claims disabled people are connected together by a 'shared experience of oppression and social exclusion' (p. 503); she also questions the validity of perpetuating the notion of a single disability identity. In fact, she sees the benefits in 'considering disability identity as multi-faceted and fluid...' (p. 504).

In what appears to be a synopsis of 'fundamental questions' that need to be asked when analyzing disability identity, Watson (2002) questions whether shared experiences represent social categories for disabled people or whether disabled people actually identify themselves by these categories; leading to further queries (mentioned above) on whether disabled people know who they are because of their impairment, because they face social discrimination or because of who they understand themselves to be (p. 512).

Watson (2002) in his study found that disabled individuals try different modes of adjustment arising out of their personal views about their condition that affect their self-identity. He found that for the majority of participants in his study, impairment is 'sidelined'. They do not perceive their impairment to affect their sense of identity even though they recognize it. Their identity is defined by what they do (not how they do it) as well as choosing to reject stereotyped characteristics. In this instance, identity is seen as a 'product of self-determination, autonomy and choice' (p. 515). For others, identity is defined as the 'product of their relationships' and 'social roles'. This concept that relationships shape identity is not unique to the disabled and therefore impairment is not a criterion for identity formation (p. 516). Watson notices how a few disabled people neither sideline their impairment nor identify themselves according to their inter-personal relationships, but instead identify their self by restructuring their idea of what is normality (p. 519). They dispute society's definition of what it is to be normal and what a normal body is. Although they accept their impairment and recognize their difference, they also see themselves as being similar to the able-bodied. They neither passively adopt an ascribed identity, nor distance themselves from their impairment and what it
means to be impaired. With these participants, identity is the 'product of a conscious action, and it is through this reflexivity that [they] exhibit[s] [their] bodily agency' (p. 520). Regarding a few female participants, Watson observes how 'incorporation of impairment into constructions of self-identity' (p. 522) distorts their perception and negatively impacts on their sense of self. These women blame all of their problems on their impairment; ranging from interpersonal relationships to inaccessible buildings. Watson notes that they fail to recognize those aspects of life that are beyond their control, regardless of impairment, and make unrealistic demands on themselves which result in a damaged self-identity (p. 523). Although Watson's observations on the incorporation of impairment into constructions of self-identity involve a minority of women in his study, this issue will be explored in my study where very specific societal expectations are imposed upon Saudi women who may blame all personal shortcomings on their impairment rather than the rigid standards placed upon them.

It appears from Watson's (2002) study that a single disability identity cannot exist since it depends on disabled people's perceptions of their impairment. It is evident that their perspectives of their condition vary even though they share a common experience of marginalization. Despite this common experience, disabled people cannot claim to have a single identity based on impairment alone.

Recognizing the differences found amongst disabled people, Shakespeare (1996) cited in Reeve (2002: 503), warns of the pitfalls in ascribing a single essentialist disability identity to persons with impairments and ignoring other characteristics, e.g., race, gender, class, etc. that distinguish one impaired person from another. For example, when gender issues are involved as in the case of Saudi women, impaired men may experience less marginalization than impaired women in a society that generally restricts the activities of able-bodied women. This suggests that not all disabled people experience the same social barriers or the same degrees of discrimination. These various characteristics and varying degrees of structural disability have an impact on the disability experience as well as the disability identity. It can then be argued that disabled people may have fragmented disability identities rather than a single/shared one.

Identity politics

Disability theorists reveal that conflicting concepts about 'the nature of identity have had a number of practical and political implications' (Riddell and Watson, 2003: 10). There is a crucial transition taking place in identity politics from the activists' assertion of a single/shared identity to the disabled individuals' 'celebration of difference' (Morris, 1991). The disability movements that originally were in the forefront of the struggle are now being criticized for denying the existence of differences amongst the disabled. This rift between the sociopolitical movements for disabled people and disabled people themselves is illustrated in recent literature which discloses that the disagreement lies in their different agendas: disability movements (or identity politics) claim a single identity for their constituents in order to promote a general consensus on issues based on perceived commonalities; whereas, disabled individuals are generally attempting to adjust themselves to their personal experiences and construct their
own identity that is shaped by different characteristics (race, gender, etc) (Barnes and Mercer, 2003). Their attempts at constructing a personal identity can be best summarized in Peters' (1996) self-reflection about her shift in focus away from disability towards impairment: 'I began a search for self-identity that is more complex and personalized, and more grounded in sense of physical and psychological self-image than in the political identity that had previously consumed my thoughts and activities' (p. 215).

Despite criticism lodged against political organizations, Barnes et al. (1999: 175) credit the disabled people's movement for its role in developing a strong disability identity. They argue that political tactics taken in an organized effort to counter social and environmental barriers has not only enabled disabled people to take direct action to gain reforms, but has also directly challenged prevailing stereotypes, e.g., passivity, timidity and weakness. When disabled people take direct action, they are assertively rejecting these ascribed characteristics and constructing their own disability identity.

Empowerment is another important aspect that direct action has on the wider process of developing a disability identity. When a group of disabled people confront dominant aspects of society and express themselves in protest, they are 'creating a sense of solidarity, purpose and collective strength' (Barnes et al. 1999: 176). Barnes et al. remark how empowerment of disabled people further benefits the aims of the movement by creating a positive shared identity which helps to recruit disabled people who may not personally relate to the movement. This process of identity development through engaging in direct action may not only change the self-perceptions of disabled people, but can also effect how society perceives them, which can ultimately change how they are treated by society at large.

**Failure to incorporate impairment and personal experience**

The disabled people's movement has achieved positive reforms by establishing specific criteria that define disability that form a single/shared disability identity. However, disabled people question the continued validity of the movement's strategy that fails to incorporate impairment into UPIAS definition of disability (Barnes et al. 1999: 91). The reason for separating disability from impairment (discussed earlier) is 'a pragmatic attempt to identify and address issues that can be changed through collective action, rather than medical or other professional treatment' (Oliver, 1996: 48). Whereas, Williams (1999) asserts that 'in bypassing the body, disability theorists have tended to assume... a homogeneity of interest between themselves and those whose interests they claim to represent' (p. 810), which may keep many disabled individuals from 'self-identifying' with others and joining movements which they believe to homogenize their identity and universalize their experience (Barnes and Mercer, 2003: 129). Purposely ignoring bodily difference between the disabled and non-disabled as a matter of political strategy remains a controversial issue, especially amongst disabled feminist writers who criticize disability theory for ignoring personal experience (Barnes et al. 1999: 91).

In her call for the 'celebration of difference', Morris (1991) asserts the need for disability activists and theorists to acknowledge the bodily differences that
distinguish disabled people (specifically, disabled women) from the non-disabled: 'But we are different... we do not reject the differences which are such an
important part of our identities... it is important that we are explicit about the ways
in which we are not like the non-disabled world' (pp. 16-7). It is important to note
however, Morris has been blamed for 'obscuring' socially constructed differences
among disabled women (Thomas, 1999: 108). In support of Morris, Thomas
reasons that in order for Morris to support or reinforce the disabled people's
movement where disability identity is the key component of the cause (pp. 108;
113), she may have decided that a shared identity in feminist disability politics is
more important than evading the creation of 'new shades of universalism' (p. 109).

 Disabled people have also linked the failure of disability movements to
incorporate impairment with its denial of personal experiences (Barnes et al. 1999:
91). They condemn the social model approach for focusing on the 'public
experiences of oppression... at the expense of the more personal experiences of
oppression which operate at the emotional level' (Reeve, 2002: 495). Morris
(1991) reasons 'while environmental barriers and social attitudes are a crucial part
of our experience of disability... to suggest that this is all there is to it is to deny
the personal experience...' which includes mental and emotional fears caused by
physical limitations (p. 10). Proponents of extending the social model approach to
include personal experiences assert that disability identity is formed from both
disability and impairment experiences which vary amongst individuals (Reeve,
2002: 504). Williams (1999) is such a proponent who claims that the critical
realist perspective is an alternative approach that can bridge the gap between the
opposing perspectives of the medical sociologists and disability theorists. He
contends that this approach is 'more integrative' and 'less antagonistic' than the
other approaches by eliminating the 'body/society and agency/structure' (p. 798)
dichotomies that obscure the understanding of a more comprehensive disability
identity. By recognizing the personal as well as the public experiences of the
disabled, comes the understanding that 'identity is at the interface between the
personal that is thoughts, feelings, personal histories, and the social...' (Vernon,

The post-structuralism of the late 20th century cantered on difference and its
influence on disability theory and identity politics has switched focus from making
distinctions between disabled and non-disabled people to identifying differences
within the disabled population (Barnes and Mercer, 2003: 78). This change in
perspective challenges the relevance of the single/shared identity in disability
theory and legitimizes the multiple or fragmented identity concept by
acknowledging the experiential divisions amongst disabled people, e.g., class,
genre and race. Peters (1996), recognizes the value of this perspective because it
encourages disability theorists to 'return to the source', in other words, listen to the
disabled people themselves in order to gain new insight into the nature of
disability identity. In this way, traditional assumptions about disability are
challenged and cast aside for 'an insider's counterpoint' (pp. 222-23).

However, the post-structuralist claim that identity is 'not fixed but fluid and ever-
changing in a process of construction and maintenance' (Thomas, 1999: 112) poses
a significant problem for identity politics which defines the disability identity by a
fixed unifying quality for the purpose of joining different people together (p. 114).
A deconstructionist approach which 'challenges the idea of [a] unanimity of a
disability collective’ (Watson, 2002: 525) may appeal to disabled people who do not self-identify with other disabled people; but in effect, undermines the power of the disability movement. On the one hand, it is argued that in order for the disability movement to be effective, disabled people have to embrace a shared identity. Yet on the other hand, Reeve (2002: 505), notes that there is validity to the argument that the movement does not represent a full range of impaired people and therefore needs to discard the single/shared disability identity and recognize the fragmented identity that includes both disability and impairment experiences.

Conclusion

In order to understand disability identity, I needed to examine western theoretical approaches and determine if the conceptual issues raised in the literature are applicable to Saudi women with ESRF. Since there is no Saudi literature dealing with this subject and there is no socio-political movement representing disabled people in Saudi Arabia, I resorted to western literature on disability movements and the development of disability theories.

It is the disabled people's movement, in general and the feminist movement, in particular, that has influenced the western perspective concerning disabled women and the formation of their disability identity. It is documented and referred to above how these movements were the impetus in shaping disability studies and shaping western policy implication. Disability theorists have assumed that disabled people have a single/shared identity based on society's response (or lack of response) to them. They consider the existence of structural barriers as the common denominator that brings all disabled people in to alliance with each other. However, many disabled people, particularly women, have rejected this social model of universal characterization. Instead, they distinguish themselves from other disabled individuals by asserting their differences, i.e., gender. Many disabled individuals, identify themselves according to their multiple/fragmented self which affects their personal experience. By doing so, they challenge the theorists' notion of a unanimous collective that claims to be the disability identity.

There is an ongoing debate that without a single/shared disability identity, identity politics will erode and disability movements will lose their socio-political impact. However, proponents of the idea that the social model of disability identity must include both the impairment and disability experience argue that the movement will become more representative of its members. They further contend that rather than being politically divisive, recognizing differences amongst disabled people can actually unify the movement.

I agree with western sociologists who assert that personal experiences of disabled individuals should be considered when examining the formation of their disability identity. Since personal experiences incorporate both disability and impairment experiences, they vary amongst individuals. This is the reason why I will utilize qualitative approach to examine issues related to Saudi women with ESRF. This approach will enable me to explore the subjective experiences of each participant and identify how they manage their illness and adjust to their everyday life.
Chapter Four
Saudi Society, Family Structure and the Position of Women

The aim of this chapter is to concentrate on the socio-cultural aspects of Saudi Arabia; how they affect the status of Saudi women; and how the socio-religious norms shape their identity. Since there is no current literature on identity formation and factors that disrupt identity regarding Saudi women, western concepts are employed as points of reference in relation to Saudi culture.

Geographical information on Saudi Arabia

The Kingdom of Saudi Arabia (Appendix A) is situated in the Middle East, and occupies four-fifths of the Arabian Peninsula. It is bordered by the Arabian Gulf, United Arab Emirates and Qatar on the east from; Red Sea on the west, Kuwait and Jordan in the north; Yemen and Oman on the south (Ministry of Economy and Planning (MOEP), 2006: 12).

The Kingdom of Saudi Arabia is divided into four regions: the western region includes the religious centres of the country: the two holy cities of Mekkah and Madina. The western region also includes the city of Jeddah (also known as the Bride of the Red Sea), which is considered the busiest commercial centre and the port of entry for millions of pilgrims every year. This makes Jeddah the most cosmopolitan city in the Kingdom and the focus of the country’s development. This region is particularly important, as it is the study area of my research. The central region includes the capital city of Riyadh; the eastern region is the focal area of the country’s petroleum resources situated in Dahran; and the southern region, includes the agricultural lands of Al-Baha (MOEP, 2006: 12). The climate for most Saudi Arabian cities is hot, humid and dry, due to the vast desert landscapes.

Demography

From the 2004 Population and Housing Census, the total estimated population of Saudi Arabia is 22.6 million, of which 16.5 million or (73%) are Saudi citizens, and 6.1 million or (27%) are non-Saudi citizens (MOEP, 2005-9: 182). Male Saudi citizens are (50.1%), while female Saudi citizens are (49.9%) of all Saudi citizens. Male non-Saudi residents are (69.4%), while female non-Saudi residents are (30.6%) of all non-Saudi citizens (MOEP, 2006: 2-3). The majority of non-Saudis are males (61%) between the ages of 20-39 years (Mishkes, 2000: 93), usually employed in the fields of production, transportation, sales and in non-skilled jobs. There are also a high percentage of other nationalities employed as domestic helpers and menial labourers, such as drivers, cleaners, maintenance workers and construction workers, mainly Filipinos, Indonesians, SriLankans, and Bangladeshis (Al-Mutari, 1998: 55). In addition, there are non-Saudi Arab women working in various institutions, such as hospitals, schools or the home.

The age structure of the Saudi population in 2004, shows that the younger age group below 15 years dominate the population representing (41%), with the lowest percentage above 64 years, only (3%). The majority of the Saudi population fall within the 15-64 years age group, (56%) (MOEP, 2005-9: 182). According to the Ministry of Economy and Planning (2005-9: 2-12) the marital status in 2004 of the
Saudi population (15 years and over, 9,929,358 total population) was (36%) never married; (60%) married; (1%) divorced; and (3%) widowed. The high proportion who are never married and the low proportion widowed, primarily reflects the relatively young age structure of the Saudi population. The fact that only (1%) are divorced reflects the general cultural unacceptability of divorce in Saudi society.

The fertility rate among the older-generation of women was estimated at an average of 6-7 children per woman (Doumato and Posusney, 2003: 78; Al-Torki, 1986: 59), which may have been due to early marriages for girls 'from the time they reach puberty' (Mackey, 2002: 149). The majority of Saudi women in the past got married between the ages of 15-18 years (Yamani, 1996: 51), but today due to increases in education, they are marrying between 25-29 years of age (MOEP, 2005-9: 182). However, the poorer the woman, the younger she marries (Mackey, 2002: 149). Although, Saudi Arabia used to be regarded as having one of the world's highest birth rates (Mackey, 2002: 404) with an estimated average of 6-7 children, recent statistics indicate a drop in the number of children to an average of 4.8 per woman (MOEP, 2005-9: 182).

Saudi Arabians enjoy a relatively high life expectancy rate at 74 years of age. For males it is 72 years and females it is 74 years (Ministry of Health (MOH) 2006: 27). The literacy rate for males is (84.2%), while for females is (69.5%) (World Fact Book 2006: 14, Saudi Arabia). The illiteracy rate varies considerably from region to region (MOEP, 2005-9: 191). Illiteracy remains concentrated in the generation over the age of 30 years (Doumato and Posusney, 2003: 249). Islam is the religion and Arabic is the official language of the country.

Development plans for Saudi Arabia's modernization

Abdulaziz Ibn Saud, who became the first king of the country, united the different regions of the Arabian Peninsula and founded the Kingdom of Saudi Arabia in 1932 (Al-Hakeel, 1999:18). The discovery of oil in 1938 proved to be a turning point for Saudi Arabia, both internally and externally. Oil had a huge impact on the social structure of the country. The way of life and habits of the Saudi people changed as they began to move from tents and mud houses in the desert, to brick houses in the city. Many individuals were employed by the oil companies which provided salaries and a new source of income (Al-Rasheed, 2002: 92).

Saudi Arabia presented a unique picture in the mid 1960's; it was very wealthy yet underdeveloped (Al-Rasheed, 2002: 121). There was a great need for modernization in terms of housing, electricity, transportation and education. In 1964, Prince Faisal was proclaimed king and immediately implemented major development plans, focusing on political, economic, social and educational programs. The government began to instigate a series of five-year development plans over a 30 year period, to develop all areas of society. The first plan in 1970 focused on providing an infrastructure and basic government services, i.e., health and education. In order to build the country's infrastructure, human resources had to be developed. At this stage, it was necessary to recruit skilled and non-skilled manpower from outside the country. Increasingly the country became dependent on a foreign labour force from the neighbouring Arab States, such as, Egypt, Sudan, Syria, Pakistan and India (MOEP, 1975-80: 90-97).
The second plan of development (1975) focused on developing the national economy, which included, transport, electricity, water, housing and the oil industry. There was great emphasis placed on establishing a private sector to insure the continued growth of the country’s economy. A great deal of support and encouragement was provided by the government, via policies aimed at financial facilities and administrative agencies to ensure mutual growth and development of private and public sectors (MOEP, 1975-80: 90-97). By the time the third development plan (1980) was underway, Saudi Arabia was the largest national oil exporter due to its enormous increase in oil revenues. The national economy was growing at a fast pace which facilitated the development of the country. The rapid growth of the oil industry necessitated a greater influx of foreign labour force that worked to maintain this national resource (MOEP, 1980-85: 38-41).

The fourth development plan (1985) placed greater emphasis on the private business sector to play a greater role in maintaining the economic growth of the country (MOEP, 1985-90: 75-78). The private business sector was encouraged to participate in expanding the health care and school systems to support the economy that was ailing due to the decrease in the oil market. The fifth development plan (1990) made way for the private sector to involve itself in services that were traditionally considered to be within the government domain, i.e., public utilities. However, during the Gulf War (1991), the fifth plan was adversely affected by the diversion of government funds away from the development of the country, which in turn slowed down the national economy (MOEP, 1990-95: 87-93).

The continued decrease in the world oil markets and the instability of domestic and global conditions required further encouragement and support of the private sector in minimizing reliance on the oil industry by opening up other areas of commerce and creating a greater diversity in the economy. The sixth development plan (1995) focused on developing Saudi human resources by educating and training a Saudi work force. The private sector financed the increase in private schools and colleges, placing great emphasis on vocational and technical colleges. Economic growth was stimulated by policies, regulations and privatization programs that encouraged further investment by the private business sector (MOEP, 1980-5: 57-66). The focus of the seventh development plan (2000) was to strengthen and enhance the Saudi economy through 'Saudinization' that required educating and training Saudi citizens to replace foreign workers in education, health and other social institutions.

Since 1970, Saudi Arabia has witnessed three decades of intense development. Government services needed to be more efficient and adequate enough to meet the demands of the population. This was achieved by restructuring governmental agencies and ministries; and partnering with private sectors. These development plans have resulted in drastic urban development, which has raised the standard of living for Saudis (MOEP, 1975-80: 90-97).

The eighth development plan (2005) has occurred against the international backdrop of 'globalization' where developing countries such as Saudi Arabia are encouraged to adopt economic standards of the developed world in order to join the World Trade Organization (MOEP, 2005-09). Despite the numerous changes made in Saudi's infrastructure to bring about modernization of this very traditional society,
Saudi Arabia still remains embedded in the Islamic principles on which it was founded.

**Saudi family structure**

Saudi Arabia is a country that was founded on Islam and therefore the teaching and practice of the religion dictates the Saudi way of life. Islam permeates throughout society at all levels, social, cultural, political and economical. This means that the law implemented in Saudi Arabian society has to adhere to the Islamic *sharia'a* [law], outlined in the *Quran* [the revelation of Allah's [God] words] and the *sunnah* [practices and teachings of Prophet Mohammad (PBUH)] that must be incorporated into a Muslim's way of life. The *sharia'a* and the *sunnah* form the foundation for the Muslim's identity '...to guide the individual in his relationship to God, his fellow Muslims, his fellowmen...' (Abd Al-Ati, 1977: 13), as well as the social identity of Saudi Arabia. 'Saudi Arabia is a country regarded as 'traditional' and as ostensibly closer to Islamic cultural norms than the other Muslim countries' (Jawad, 1998: 29). Therefore, any discussion regarding the Saudi social structure and the status of Saudi women has to take the Islamic perspective into consideration.

Islam highlights the importance of the family in terms of identity and purpose of the individual and regards the family to be the most essential institution of society. Based on this Islamic premise, the Saudi social structure revolves around the Saudi family, in fact, the text found in Saudi’s Basic Law (Article 40), states that 'The family is the basic unit of Saudi society...' (Yamani, 1996: 268; and MOEP, 2005-9: 301). The main purpose of the Muslim family is seen as to regulate sexual activities between men and women, and secure social and economic needs of all of its members. Loyalty to the family is paramount to any other type of relationship, except to that of God. There is a strong link between society and the family, and between the family and the individual within the Islamic social structure (Abd Al-Ati, 1977: 34).

The Saudi family structure is patriarchal and hierarchical (by gender and age) in accordance with the structure of tribal heritage; the oldest males have authority over the younger males and over all women (Yamani, 1996: 82). The power of authority or legal guardianship remains with the father or husband until death; and then is transferred to the eldest son. If there is no adult male in the family unit, authority over the family is transferred to another *wali-al-amur* [legal guardian] who is either a grandfather, father, brother, son, uncle or nephew. All of these men are considered *mahram* [males related to the female by a certain degree of sanguinity]; they can never marry each other.

It is important to note that the issue of *mahram* is closely linked to the issue regarding segregation by gender. Segregation by gender stems from the religious belief that men and women who are not *mahram*, should never socialize together in order to avoid any impropriety. 'Saudis believe that any mixing of the sexes is morally wrong and not in accordance with the teachings of the *Quran* (p. 177) and 'it is felt improper for men and women to work together in the same location' (Fletcher, 1974, as quoted in Beck and Keddie, 1978: 177). Thus, segregation by gender is a general rule in Saudi Arabia, 'that touches on virtually every aspect of public and social life' (Al-Munajjid, 1997: 33). As an extension of this rule, Islamic
law dictates that Muslim women must always cover their hair and body when leaving their homes.

Since there is no preference in Islam for a particular family 'organizational form', Saudi society embraces all forms of family structure, including immediate (nuclear), extended and polygamous. It is important to note that western sociological nomenclature used to describe family as being 'nuclear' (Figure 4.1) does not accurately reflect the Saudi family structure. It is commonly recognized by family sociologists that family structure varies amongst societies. The Arabic term, al-usrah, actually means the immediate family. The key relationships of women in the immediate family are based upon their marital status and household composition. Similar to the western 'nuclear' family, single Saudi women live with their parents and siblings; married women live with their husband and offspring. However, in addition to their offspring, the household composition of the immediate family for women who are 'previously married' also includes their parents and/or siblings. This distinct difference between western family structure and that of Saudi society has to do with legal guardianship as dictated by traditional Saudi culture where 'previously married' women must move into their father's or brother's home in cases of separation, divorce and widowhood. Despite this difference in Saudi family structure, Al-usra [immediate family] will be referred to as the 'nuclear' family to avoid confusion.

The emphasis is not placed on the organizational form of the family, but rather the 'mutual expectations of the membership' (Abd Al-Ati, 1977: 20). Even though the traditional extended family structure is no longer predominant in Saudi society (MOEP, 2005-9: 315), 'family connections reaching far beyond the nuclear unit are evident in strong psychological, social, economic, and even political ties' (Al Faruqi, 1988: 41). This reliance on extended family members (including grandparents, uncles, aunts and cousins) is 'not merely a product of social conditions' (p. 41) but from commitment that is embodied in religious belief; and it is based on this belief that it remains a current practise for Saudis to require their relatives to provide economic or social support when needed, regardless of whether they are members of the immediate or extended family. However, this traditional approach actually places undue burden and stress on the present day nuclear family that faces social and economic pressures of modern Saudi society. In the face of these modern day pressures, many families fail to accommodate the needs of their extended family since their own social and economic resources are limited (MOEP, 2005-9: 302).

Another example of how current day Saudi society continues to practise its traditional socio-religious norms is associated with women's socio-economic dependence on their male guardian. This is demonstrated by requiring Saudi women to reside with a male guardian, regardless of their age and marital status. In the present day, this tradition becomes a burden upon the extended family when divorced or widowed women with children must move out of their husband's home into that of their father, brother or uncle and share the resources of the host family.

One must be reminded that even though Saudi Arabia has made some major social changes, i.e., improving women's education and job opportunities, its socio-religious beliefs still influence how family members treat one another since '...mutual expectations of individual family members are not established only by familial relationship, but also by the membership in a larger social system...' (Abd
Al-Ati, 1977: 21). Even though these rights and obligations are administered within the privacy of the family circle, the rights and obligations of the family that pertain to 'lineal identity and maintenance, succession and affection, socialization of the young and security for the aged, and maximization of effort to ensure the family continuity and welfare' (p. 22) are a major part of Saudi religious norms. Thus, ties between Saudi individuals and their family are closely connected to Saudi society.

**Figure 4.1**

*Key family relationships of women within Saudi family structure*

<table>
<thead>
<tr>
<th><strong>Al-ahl [Family]</strong></th>
<th><strong>A. Al-usrah [Immediate/nuclear family]</strong></th>
<th><strong>B. Al-akarib [Extended family]</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>Single women</td>
<td>Married women</td>
<td>Previously married women</td>
</tr>
<tr>
<td>a) Parents</td>
<td>a) Husband</td>
<td>a) Parents</td>
</tr>
<tr>
<td>b) Siblings</td>
<td>b) Offspring</td>
<td>b) Siblings</td>
</tr>
<tr>
<td></td>
<td></td>
<td>c) Offspring</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Single women</td>
<td>Married women</td>
</tr>
<tr>
<td>a) Parents</td>
<td>a) Parents</td>
<td>a) Grandparents</td>
</tr>
<tr>
<td>b) Siblings</td>
<td>b) Siblings</td>
<td>b) Uncles and aunts</td>
</tr>
<tr>
<td>c) Cousins*</td>
<td>c) Cousins*</td>
<td>c) Cousins*</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td><strong>NB:</strong> <em>Male cousins are non-mahram therefore permitted to marry participants</em>*</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>C. Al-arham [In-laws]</th>
<th>(All relatives by marriage)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Married women</td>
<td>Previously married women</td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td>All relatives of participants’ husband (including ex-husband's relatives)</td>
<td></td>
</tr>
</tbody>
</table>

Unlike modern western society, Saudi society still follows the custom of arranged marriages. The ideology underlying this custom is that Saudis consider the good of the wider family to be paramount to the happiness of the individual. An ideal marriage is seen as a marriage among relatives, particularly first-degree kin where relatives marry to consolidate two families for the benefit of one another (MOEP, 2005-9: 307). Marriages between cousins remain prevalent in Saudi society for this reason, even though many families are moving away from this tradition in order to avoid various congenital problems. Findings from the 2000 Saudi Family Health Survey indicate that the preference for this pattern of marriage decreases the higher the level of education of the female. Thus, the rate of marriage to a relative among women who did not attend school at all is (58%), compared to (50%) among women who completed primary school and (36%) among female university graduates (MOEP, 2005-9: 307).

Another aspect of the social structure in Saudi society is the recognition of polygamy as a legitimate form of family organization. In Islam, men are permitted to marry up to four women at the same time. However, in the *Quran* (Surah Al-
Islamic law permits both men and women the right to divorce. However, in hadith [narratives of Prophet Mohammad's life], it is stated that, 'the most hateful thing to Allah [God] is divorce' (Al-Munajjid, 1997: 24). Thus, Muslims may divorce, but it is discouraged by both family and society. Nevertheless, one side-effect of modernity found in Saudi society is the rapidly increasing divorce rate as reported by the Ministry of Justice (Ministry of Justice, 2006: 217). To date, no data has been gathered concerning the causes of divorce or the educational and economic background of partners in divorce cases (MOEP, 2005-9: 308). Although there are no published statistics, it is worthwhile to note that there are Saudi women who are not living with their husband (separated) yet are not legally divorced. Since the Saudi government only recognizes divorce as a legitimate marital status, couples who are separated are included in the married category. This is also linked to Saudi families discouraging divorce in order to give estranged couples time to reconcile their differences.

In cases of divorce 'child custody laws generally give priority to the father over the mother after the child is weaned or later in childhood' (Doumato and Posusney, 2003:10). The age when children are required to live with their father varies depending on the school of law followed by the family, e.g., custody of children six years or less remain with the mother unless she remarries (Roald, 2001: 232). Those children who live with their divorced mother move in with her legal guardian. However, if a woman remarries, the children move in with their father or his family. Financial maintenance of the children is provided by the father as long as it is needed; and unlike Western custom, regardless of age, Saudi children continue to live in their father's home until they marry. Since remarried women are considered statistically as married women, there is no data that shows the number of divorced women who remarry. However, since it is religiously and culturally acceptable for divorced and widowed women to remarry, therefore it is not unusual for Saudi women to remarry in cases of divorce or widowhood.

Status of women in Saudi society

Despite the economic wealth and advanced technology that is developing in Saudi Arabia, women's education and employment opportunities lag behind those in neighbouring Arab Muslims States. When comparing women's opportunities in the
various Gulf States, Yamani (1996) finds that Saudi women 'are the most deprived in the Gulf region. Saudi Arabia implements very strict rules concerning women and the family' (p. 257). The reason for this is that even though Saudi Arabia is rapidly becoming a technologically advanced country, the government still maintains the importance of upholding traditional Islamic values and Saudi customs, which influence women's status in society. It is urgent to recognize that Islamic law does not forbid women from seeking education; on the contrary, it is seen as their religious right. In fact, Islam has given women the right to run their own business and trade (Naseef, 1999: 102). It was therefore due to social customs that education for Saudi women was not introduced until the 1960's, when the first school opened in Jeddah. Originally, the policy for girl's education was not to enable women to work outside of the home. Instead, the school's main objective was 'described as producing better mothers and homemakers' (Yamani, 1996: 269). It was during the late 1980's, that there was a shift in girl's education to encourage some Saudi females to pursue a higher education in teaching and medicine. However, women are still not permitted to study certain majors, such as law, engineering, geology and petroleum (p. 270). Even though today, some women may travel abroad in order to specialize in such fields of study, employment for women in these areas remains non-existent in Saudi Arabia, because they are considered inappropriate professions for women (Doumato, 1992: 35). Although, choices of professions for Saudi women have been restricted to medicine, education and social services (Doumato, 2000: 22); today, women's choices have expanded to include banks and other sectors that cater to women's needs.

Even with the relatively late start of girls' education, the rate of enrolment of females in all educational levels has increased sharply. The average annual rate of increase of total female enrolment was 8% over the 1975-2002 period compared to about 4.2% for males. Thus the gender gap in educational enrolment was closed at the secondary and university levels in 2002 and at the primary level in 2003 (MOEP, 2005-9: 325).

However in 2003, the rate of female employment is estimated at only 14% of the entire Saudi labour force (MOEP, 2005-9: 327). A characteristic of Saudi employed females is the predominance of the young age group between 25-34 years which account for 54% of the total number of working Saudi females. The remaining Saudi female labour force is comprised of 13% between 15-24 years; 29% between 35-49 years; 3% between 50-59 years; and 1% over 60 years (p.328).

According to the latest development plan, women's limited involvement in the Saudi labour market still exists due to the limitations of work opportunities (MOEP, 2005-9: 160). Although Saudi society has made education and certain forms of employment accessible to women, the question of a woman attending school or entering the workforce still depends on the written consent of her male guardian regardless of her marital status and age. 'In the case of Saudi Arabia, female education, work and, for that matter, any economic activity, is tied to the consent of a male guardian; therefore, we find that many women are unable to take advantage of the few benefits made available to them' (Al-Mana, 1981: 27-28).

In today's Saudi society, female education as well as employment is a common topic of discussion within the family. However, only a small percentage of guardians permit their female relatives to work outside the home. This may be due to the
traditional Saudi custom that restricts females from travelling in public without an escort. This custom is reinforced by practical obstacles that society perpetuates with its limited public transportation service and legal prohibition of women drivers. Even with their guardian's permission to work, unless these women have a driver to take them to work, they are unable to participate in economic activity. In theory Saudi women are able to seek education and paid employment; yet the typical restrictions on travel are a constraint on women's rights to become educated and employed.

Issues about the role of Saudi women in the labour force are still politically contentious, especially concerning married women. Although marriage was once viewed as a major impediment to entry of women into the labour force, comparative data confirms that extensive changes have occurred in this respect (MOEP, 2005-9: 329). Recent data on working women reveal that (69%) of employed females are married. This data demonstrates the present trend to strike a balance between participation of women in the labour market and their role as housewives (p. 329). However, in order to support working married women, the government must implement special provisions, e.g., maternity leave, providing nurseries and allowing temporary absence from work, to enable them to join and remain in the workforce while supporting their family care-giving role as mother and wife (MOEP, 2005-9: 329).

Regardless of the trends to increase women's employment in Saudi society, the importance of women's care-giving roles remains a priority. Naseef (1999) emphasizes that a woman's 'work must not consume her entire time and energy, thus preventing her from fulfilling her more important role as wife and mother' (p. 102). Naseef prioritizes the roles of wife and mother, yet acknowledges a woman's need to be actively involved in the community by encouraging her to participate in education and work around her roles as mother and wife.

**Saudi women's family roles**

Although Saudi women are now permitted to participate in the workforce, they still must fulfil their traditional roles as a wife and mother. They are bound by religious obligation to perform their duties in this capacity: 'to a great extent relationships in the family are governed by Islamic principles such as... protection of the family...' (Anwar, 1987, as quoted in Roald, 2001: 87). She takes charge of domestic affairs that include: providing a comfortable atmosphere in the home, upbringing and moral education of her children, caring for her husband, maintaining the family and home, and providing comfort to relatives (e.g., visits, entertainment, caring for the ill). Just as important, a Saudi woman is expected to uphold the reputation of both her father and husband: as bint-al-nas [daughter of reputable people] she is required to conceal their faults and weaknesses, as well as protect herself from gossip and criticism.

The responsibilities and difficulties that a wife/mother has to shoulder are acknowledged in society; and husband and children are expected to show her gratitude, kindness and companionship, 'for... her role as wife and mother is considered the most sacred and essential one' (Badawi, 1975: 141).
Wives are described in the Quran as being Allah's creation, whose purpose is to provide men with peace:

'...He created from you wives from amongst yourselves, so that you may find serenity and tranquillity in them. And He has put between you love and compassion... ' (Surah Al-Rum 30:21).

Mothers are also entitled to the utmost respect and obedience from their children. In a hadith [narratives of Prophet Mohammad's life] pertaining to the important position of a mother, the meaning of her highly elevated status is commonly stated as 'paradise lies at the feet of your mothers', which children of all ages are not allowed to ignore.

Even though Saudi social custom dictates that the father (or other male guardian) ultimately approves of his child's marriage, it is the mother (or sister) who usually selects the woman who may become the prospective bride. The mother plays the most important role in this matter because in a gender segregated society, she and not the male guardian is allowed to see the prospective bride (Al-Munajjid, 1997: 78).

The role of daughter is also important in Islam. Saudi women must show kindness and respect towards their parents throughout their life. This includes taking care of them as needed, especially during old age. In Islam, this is known as birr, and it is believed to be rewarded greatly in the after life, and therefore, encouraged. 'Many ayats [verses] of the Quran describe pleasing one's parents as coming second only to pleasing Allah' (Al-Hashimi, 2000: 141).

Saudi women must also fulfil their responsibilities towards the extended family by playing a major role in preserving strong family relationships. They not only have to be aunt to their nieces and nephews, but also at times required to play the role of mother to them. They are therefore, the first port of call in any family emergency or social occasion. Failure of women to fulfil any of their roles would not only be detrimental to their wider family relationships, but also to Saudi society as a whole. Thus, Saudi women are seen as the foundation of the family institution and it is through their numerous roles that they maintain strong family ties.

It has been described above how the roles of Saudi women are vital to the foundation of Saudi society. Since there is no literature dealing with issues regarding Saudi women's identity based on their family roles, my role as a sociologist, who is both Saudi and female, becomes particularly pertinent and crucial. I believe it is necessary to approach this subject from the Saudi perspective primarily based on socio-cultural values originating from the Islamic belief system.

Identity of Saudi women

The western essentialist approach to understanding the nature of identity where there is an assumption that an individual's identity is comprised of essences or fixed qualities is compatible with Saudi socio-cultural norms that are shaped by Islamic beliefs which recognize the essential biological, psycho-emotional differences between men and women. Essentialism implies that 'natural sexual
difference is used to explain social differences. Inequalities between men and women are justified on the basis that men are stronger and more logical, women are better at caring' (Greenwell, 2003: 99). In both cultures, 'sex' refers to the biological distinctions between male and female; the concept of 'gender' (Oakley, 1972) in western literature refers to the socially constructed differences between men and women that are labelled 'masculine' and 'feminine'.

Since the issue of gender differentiation is based upon culture and its social significance varies accordingly, the distinct perspectives of the West and Saudi Arabia on this issue must be examined. As Greenwell's above quotation suggests, the West implies that different treatment and expectations of individuals based on sex implies a sense of inequality or inferiority; whereas, Saudis believe and accept that God has created the essentially different natures of men and women, asserting that '... although women and men are spiritually and morally equal, they have complementary rather than identical roles and responsibilities' (Henley and Schott, 1999: 512). Based on Islamic religion, sex is seen as determining particular rights and obligations of an individual, and differences in rights and obligations do not qualify an individual as being either superior or inferior to another. Within this socio-religious context, differences based on sex are not considered a social barrier or social oppression. Instead, it is seen as serving the needs of a culturally traditional society, e.g., grade twelve female students in government schools are provided texts that reinforce the concept of 'women's nurturing roles...' (Doumato and Posusnay, 2003: 248). Cultural identity is very strong, such that Saudi women either identify themselves as wife and mother or hope for a future that includes marriage and motherhood; for a 'young Saudi woman... marriage is her reason for being, the ritual that will allow her to fulfil her ultimate destiny, that of a mother' (Mackey, 2002: 151).

In Saudi society, the gender roles of wife and mother based on being female (biological differences) illustrate how 'socially constructed differences overlie essential bodily differences' (Thomas, 1999: 106). Therefore, it is both the biological essence of being female; and the socially constructed differences of gender-based roles that ultimately shape Saudi women's identity.

Saudi society, unlike Western societies, encourages and perpetuates amongst its members a gender differentiated, but otherwise homogeneous social identity where similarities are emphasized and individual differences are discouraged, e.g., according to Saudi custom, both men and women are required to wear traditional outer garments in public; for men: white gutra [head cover] and thobe [long white garment worn in public by all Saudi men]; for women: black tarha [head scarf] and abaya [the black outer garment required to be worn in public by all Saudi women]. Similarity in outer appearance promotes a homogeneous identity in public, but not necessarily in the private sphere. In addition, time schedules at work, school and shopping are fixed around the five daily prayers so as to remind all Muslims that it is time for them to cease work or play in order to fulfil their religious obligations. These socio-religious customs that dictate the Saudi social identity, encourages uniformity that is crucial in a homogeneous society, regardless of any personal differences, i.e., in income, occupation, or health condition.
A number of writers argue that the characteristic of a homogeneous society such as Saudi Arabia is to reinforce a single/shared identity. This is particularly illustrated in the roles of Saudi women as wife and mother. Saudi women's identity is inextricably entwined to these roles, so that regardless of a disability, women are expected by society, as well as themselves, to continue to fulfill them. Their roles are vital to sustaining Saudi traditions. Swain et al. (2003), note that in certain cultures '... individuals are expected to put the good of the community above their own wishes and interests. Religious values... may be deemed more important...' (pp. 76-7). More specifically, Mackey (2002), declares that in Saudi society, the 'concept of individuality is absent' (p. 109). As a researcher of traditional Saudi society, she notes a primary distinction between Westerners and Saudis: a Westerner's identity is bound up in 'the intense individualism of Western society', whereas, a Saudi's identity is closely connected to the cohesiveness that bonds the Saudi family together where decisions are not made independently but by the patriarch (p. 109). In Saudi society, 'the absence of any independent choice is in no way perceived as doing damage to the individual' (p. 109), because sharing values and experiences are integral in preserving a homogeneous society. Therefore, Mackay argues that the ongoing debate in the West about the existence of fragmented/multiple identities as opposed to a single/shared disability identity does not pertain to the disability experience of chronically ill Saudi women who have always possessed a single/shared identity.

Admittedly, the argument that Saudi's have a homogeneous social identity is not in accordance with the western notion of an identity that is in a 'context of diversity and fluidity' (Vernon, 2003: 56). The Saudi perspective that their identity is based on fixed similarities (socio-religious values) that fall outside of time and place contradicts Vernon's characterization of 'identity is a matter of becoming rather than simply being' (p. 56) and Hall's (1990: 225) assertion that identity is not 'eternally fixed in some essentialized past...'. In fact, being Saudi is what essentialists refer to as an 'intrinsic meaning to identity' (Watson, 2002: 509), where being born a Saudi boy or Saudi girl automatically makes them Muslim whose socio-religious values form their identity and ultimately dictate their roles. Thus, the post-modern notion that disabled people have fragmented/multiple identities based on varied socially constructed differences (i.e., religion, ethnicity, etc.) may not apply to Saudi women.

Conclusion

It is important to understand the socio-religious traditions of Saudi society in relation to women in order to understand the identity of Saudi women, in general, and chronically ill and disabled Saudi women, in particular. The identity of Saudi women is shaped by a traditional society that is greatly influenced by Islam, which teaches that family is pre-eminent and women's family care-giving responsibilities are paramount to all other duties; and it is through these numerous roles that women maintain strong family ties. Since Saudi women are the bedrock of their family and vital to the foundation of Saudi society, failure to fulfill any of their roles is seen as not only detrimental to their family relationships, but also to Saudi society as a whole. As chronically ill women's abilities to manage these roles and
responsibilities diminish over a period of time due to their illness, it is crucial to
determine how their identity is affected. Thus, the impact of chronic illness,
particularly ESRF, on women’s family care-giving roles and relationships will be
assessed within this context.

Even though disabled Saudi women may share similar issues with disabled people
in general, in terms of impairment, social barriers and self-perception, the
distinguishing cultural factors that shape the identity of Saudi disabled women
needs to be explored. This chapter has discussed how Saudi society defines the
Saudi female identity in a rigid and fixed way because societal expectations are
the same for all women (regardless of disability), according to their culturally-
assigned gender-based roles and responsibilities. Thus, impairment may not have
much impact on women’s identity as long as they are able to manage their socially
constructed roles and relationships as wife and mother. However, when Saudi
women with ESRF are unable to manage their everyday life, impairment and
chronic illness is likely to become a disruptive factor that may affect their self-
perception, self-concept and ultimately their identity.

Notwithstanding Saudi women's single/shared identity based on their traditional
socio-religious values, socially constructed differences do exist, such as socio-
economic ones. These differences must be acknowledged when examining the
importance and availability of resources for Saudi women with ESRF who rely
heavily on family for financial and practical services. It is also vital to explore the
socio-economic disparity amongst chronically ill Saudi women in order to fully
understand their illness experience and how they adjust to the disruptive event that
effects the practical management of daily life and social relationships.
PART II
METHODOLOGY
Chapter Five

Quantitative Survey of Women Undergoing Haemodialysis

The previous literature review chapters discussing the various theoretical concepts and approaches to developing an understanding of chronic illness and disability provided a guideline for my empirical study concerning the impact of ESRF on the everyday life of chronically ill and disabled Saudi women.

The aims of this study are to explore gender-related issues that affect the various aspects of chronically ill and disabled women's life; to examine the impact ESRF has on their quality of life, as well as their perceptions of themselves and their illness (body image, self-concept and identity) that may prove to be detrimental to their family care-giving roles and relationships; and to determine how they manage their everyday life. Although these concepts have been highlighted in western sociological literature, this study critically re-evaluates them in the light of the socio-cultural differences found in Saudi society.

Using multiple methods

At the initial phase of research, I realized that there were no studies or accurate and complete data available regarding Saudi women with ESRF. Since there was a need to gather background information on these women, I planned a quantitative survey to collect data on their socio-demographic characteristics. In addition qualitative interviews are important to inquire deeper into the participants' life in order to understand their illness experience and the extent to which ESRF affected their roles and inter-personal relationships. Although these two methods were used to gather different types of data, they are complimentary to each other and were used for the purpose of 'facilitation' whereby one research strategy is employed to aid research using another strategy (Hammersley, 1996, cited in Bryman, 2001: 447).

Based on Morgan's (1998b, cited in Bryman, 2001: 448) criteria for classifying approaches to multi-strategy research: the quantitative method was used as the 'principal data-gathering tool' for collecting socio-demographic data 'to inform the design of another method [qualitative] with the latter [qualitative] often seen as more significant for answering the research question' (Moran-Ellis et al., 2006: 49). My aim was to 'know more' about the respondents' demographic characteristics before obtaining data about their illness experience, therefore the 'sequence' I followed was first the quantitative then the qualitative method.

In agreement with Moran-Ellis et al. (2006), I chose a methodological approach that would enable me to generate appropriate types of data that will reveal different aspects of the social reality of women suffering from ESRF. Utilizing both quantitative and qualitative methods enhanced my understanding of their social world. Using qualitative interviews to gain insight into their illness experience revealed the complexity of their circumstances at both the macro and micro levels (Kelle, 2001). I was therefore be able to examine their illness experience and self-perception according to their position within the social structure of Saudi society. I agree with Kelle's assertion that it benefits a study to integrate quantitative and
qualitative methods in order to render a more comprehensive sociological explanation of a phenomenon (p. 45). Another reason for using multiple methodological approaches was to present to policymakers a more precise outline of the support resources that chronically ill and disabled Saudi women need to improve their quality of life.

Having chosen to use both the quantitative and qualitative approaches in my study, I have divided the Methodology section into the following two chapters: Chapter Five discusses the quantitative approach of utilizing a survey questionnaire to collect descriptive information about all women suffering from ESRF and receiving haemodialysis at JKC over a three-month period. Chapter Six will discuss the qualitative approach using in-depth interviews to elicit narratives about the illness experience of these Saudi women.

This chapter discusses the methodological procedures to be used in designing, developing and implementing the survey questionnaire; pilot study, population under investigation, ethical considerations and the analysis of the survey data.

**Population under investigation**

My aim was to obtain a concise demographic profile of the population under investigation: all women with end-stage renal failure and receiving haemodialysis therapy in the Jeddah Kidney Centre (JKC) located in the city of Jeddah, Saudi Arabia. This site was chosen for my research because it is the largest government-subsidized referral kidney dialysis centre in the Kingdom under the management of the Ministry of Health (King Fahd Hospital: Achievement Report, 1998: 70) which provides free medical services for all patients. This provided easy access to a readily available pool of renal patients to research.

In Phase I, I decided to administer a questionnaire at the JKC during a three-month period to all women with end-stage renal failure and receiving haemodialysis therapy in order to obtain survey data for all women. All members of the population under investigation were attending one of the four dialysis shifts, spread over a 7 a.m. to 11 p.m. time period, at the JKC with a total of 25 beds in each shift.

**Designing and developing the survey questionnaire**

Primarily, the purpose of employing a survey questionnaire in my study was to 'prepare the ground for qualitative research' (Bryman, 2001: 450) by gathering factual information and socio-demographic characteristics on all women suffering with ESRF and undergoing haemodialysis therapy during a three-month period. Since 'surveys produce information that is inherently statistical in nature' (Neuman 2003: 263), a survey questionnaire will be utilized to gather a large amount of 'factual' data which will provide accurate, complete, and current data on the overall characteristics of the respondents (Bowling, 2002: 194).

Before designing the survey questionnaire, I examined both the respondent’s medical records to familiarize myself with their medical condition and their social service records to obtain information about their social background. I referred to
questionnaires used in a range of studies of health and illness for ideas about content, style and format. However, since most of these questionnaires were found in western studies, I had to design a survey questionnaire tailored to suit the aims of my research. However before implementing the final survey questionnaire, a pilot study was conducted to assess whether the style, format and content of the questions were applicable and relevant.

**Piloting the questionnaire**

I designed my own questionnaire to include both an open-ended and closed-ended question format in the Arabic language. This pilot questionnaire was presented to a total of 30 ESRF patients at government hospitals throughout Jeddah, including JKC. While personally administering the questionnaire, I realized that due to a high percentage who were illiterate, the respondents were unable to self-complete the open-ended questions. Thus, the written format was read out to each respondent on an individual basis; and as they answered, I personally filled out the questionnaire for them. Not only did I have to read aloud the original questions to them to insure a high response rate; I also had to re-word all questions for maximum clarification. The questions had to specify the exact information required from the respondents. For example, the first draft of the questionnaire asked, 'Do you receive any monthly income?' Most of the respondents were confused by this question because they did not have any personal income. A common response included income from the head of the household who supported the family. I realized that I had to reword this question to separately ask about personal income and household income, and if any, the source of income and amount of income. As questions were being revised orally, all refinements were written directly onto the first draft of the questionnaire.

In December 2003, I focused on piloting the refined survey questionnaire. This time I personally administered questionnaires to 30 ESRF patients receiving haemodialysis only at JKC. These respondents were chosen from all four dialysis shifts (7a.m.–11p.m.); and the questionnaire was administered only at JKC before or after the dialysis sessions.

The pilot study proved to be valuable because it revealed the various adjustments that were needed prior to implementing the final survey questionnaire, and also helped me to refine questions to insure a high response rate.

**Ethical considerations**

I took into consideration the ethical issues, such as consent, confidentiality and anonymity throughout my research. My research fully conformed to the BSA Code of Ethics. Before conducting my research study I had to obtain two types of consent. The first consent was needed from the Ministry of Health in Jeddah because any research projects involving medical and health institutions require the university to obtain written permission. Once permission was granted, the Ministry of Health then directed the particular institution (King Fahd Hospital) to accept the project. This consent was obtained at the very beginning of my research project. However, the second only required verbal consent from the respondents because hospital policy requires all patients to sign a consent form at the time of admission, which included research studies.
Once the respondents had been informed about all aspects of the research, a letter of introduction (Appendix B translated English version; Appendix B(i) original Arabic version) including the purpose and aims of the research was provided to the patients. They were required to sign a consent form (Appendix C translated English version; Appendix C(i) original Arabic version), designed for this study, which also stressed the anonymity and confidentiality of the information provided. Informed consent is a fundamental issue, which involves informing research respondents about the aims of the research, which in turn allows them to decide whether or not to participate in the study (Neuman, 2003: 124). Informed consent is even more important to obtain, particularly in a country like Saudi Arabia where society tends to be relatively closed to any form of scrutiny. This can be the case particularly when dealing with issues surrounding women and their personal relationships with their families.

Interestingly, the respondents were surprised when I asked them for their written consent because such decisions are traditionally made by their male legal guardians. In fact, this was the first time these respondents had ever been asked for their consent about a matter that personally involved them. Some women wanted to ask their husbands or fathers before agreeing to take part in my study. I received telephone calls from some husbands and fathers who sought further clarification regarding my proposed use of the tape recorder. After they were satisfied with the procedure to maintain confidentiality, the women finally gave their consent.

Confidentiality and anonymity are also two other ethical issues I considered while administering the questionnaire. Bulmer (2001) raises an important issue in respect of privacy where sociologists are perceived to be intrusive and invasive when conducting their research. I agree that researchers must be sensitive to the concerns of their respondents and identify what they may regard as their personal domain (p. 50). In order to preserve the respondents' privacy, a coded number was marked on each participant's questionnaire as soon as they were completed and before they were entered into the SPSS data file. This precaution will ensured that the respondents would not be identified by name or description in any future publication of the results of the study.

As a sociologist, it is ethically as well as practically important to maintain a balance between the respondents' need for privacy and obtaining their background information for my study. Without my understanding and respect for their confidentiality and anonymity, I could have been denied access to vital information from the participants for fear that their information would be publicized (Bryman, 2001: 480) or used for purposes other than my research.

**Implementing the survey questionnaire**

The survey questionnaire was implemented to all women with end-stage renal failure and receiving haemodialysis therapy across all four shifts in order to obtain survey data for all women over a three month period (April to June 2004). Each woman scheduled to receive dialysis was assigned to one particular shift: 7-11 a.m; 11 a.m-3 p.m; 3-7 p.m; or 7-11 p.m.; and on alternate days, depending on the number of dialysis sessions needed per week: either 3 times, (Saturday, Monday and
Wednesday) or (Sunday, Tuesday and Thursday); or 2 times a week (Sunday and Tuesday); or once a week. Therefore 8 or 9 different women could occupy the same bed number in a 24 hour period for one week. Since I personally administered the questionnaire for all the women, there were no refusals; so I had a 100% response rate.

The survey questionnaire (Appendix D translated English version; Appendix D(i) original Arabic version) was the instrument that I personally administered to all women diagnosed with ESRF who were attending haemodialysis therapy sessions at the JKC during a three-month period. The structured components of the survey questionnaire provided detailed characteristics of these women's age, nationality, place of residence, marital status, motherhood, education, occupation, income, accommodation and number of people living in the same household and relationship to the patient. It also included 'likert' scale type questions measuring the extent of medical, psychosocial and physical complications and signs of chronic renal failure during actual dialysis treatment and non-dialysis treatment days. These responses were categorized as 'not at all', 'slightly', 'moderate' to 'extreme'.

In order to put the patients at ease, I was first introduced by a staff member of the JKC (usually the head nurse). Then I introduced myself as a sociology researcher from King Abdulaziz University. At this time, I read aloud my letter of introduction (Appendix B) which included my name and phone number in case they needed to contact me; and each participant also received a copy. The consent form (Appendix C) was also read out to them. Although it was unnecessary for me to obtain signed consent forms due to the hospital policy of including research studies in their general release form; for ethical reasons, I made certain that all the patients verbally agreed to participate. At this time, I stressed the confidentiality and anonymity aspects of my research to further reassure them of absolute privacy during the survey process. This part of my introduction was very important because all the participants for my subsequent in-depth interviews would be selected later from this group of women.

I specifically wore a white lab coat with a hospital photo-ID clipped to it instead of the usual abaya [the black outer garment required to be worn in public by all Saudi women] so that the women would not confuse me with other patients or visitors. Wearing the lab coat in this way was not used as a tool of deception, but rather as a way to avoid confusion between myself and other strangers; the ID badge specifically identified me as a 'researcher' to avoid confusing me with the hospital-affiliated staff. In addition, I verbally identified myself as a university affiliated researcher and outlined my research goals to the respondents at the initial stages of the survey. Periodically I reminded respondents of my researcher role if they asked me for medical advice concerning their illness. I was ever mindful that despite their awareness of my professional status, they may seek my advice and intervention.

Analysis of survey data: Socio-demographic profile of all women undergoing haemodialysis

Univariate analyses were performed in order to produce frequency distributions for socio-demographic characteristics pertaining to all women undergoing haemodialysis at the JKC. Table 5.1 provides demographic information: nationality,
Table 5.1 provides the socio-demographic characteristics of all women undergoing haemodialysis (n=216) at JKC. The percentages in this table are rounded for clarity.

Nationality
The majority of respondents were of Saudi nationality, (93%); and the non-Saudis comprised of (7%).

Age
The respondents were divided into four age groups: 11% were less than 24 years, 17% were between 24-35 years, the majority of respondents (55%) were between 36-59 years, and (17%) were 60 years and over.

Marital status
Although the data reveals that the majority of the respondents (52%) are married women which reflect the general proportion of married women in Saudi Arabia, the proportion of divorced women (7%) is lower amongst the respondents than the general population (Ministry of Justice, 2006: 217). Even though separated respondents (3%) are not residing with their husband nor are they receiving any financial support from him, they are not included in the divorced category because they are still legally married. Table 5.1 also shows that (17%) are single and (21%) are widowed.

Number of children
Only 4% of respondents were childless, while (24%) have between 1-3 children, 43% have between 4-6 children, and (29%) have 7 or more children. Table 5.1 reflects the high fertility rate for the general population in Saudi Arabia (Ministry of Economy and Planning, 2005-9: 182). According to JKC doctors, all but one woman had their children prior to receiving haemodialysis.

Educational level
In terms of education, an overwhelming majority (68%) of the respondents could not read or write, which reflects the high percentage of illiteracy amongst women in the general population of Saudi Arabia. Some respondents indicated they could read and write (8%) but reported that they did not have any formal education. Of those respondents who did attend school, none of them completed that level of education. For example, those who indicated they were at the elementary level (7%) did not graduate from 6th grade; intermediate level (7%) did not graduate from 9th grade (last year at the intermediate level); and secondary (7%) did not graduate from 12th grade. It must be noted that the respondents who selected the category of college (3%) actually were referring to a teacher's institute which involved two years of training. This program could be taken after a student completed 7th grade. Today, this institute is defunct and female students who want to professionally teach must first obtain a Bachelor's degree.
Employment status
When responding to the question concerning employment, almost all respondents (95%) reported that they had never been employed and the remaining (5%) reported they were 'retired' but still received a salary which was actually 'retirement' benefits on health grounds. The overwhelming percentage of respondents not employed reflects the status of women in the Saudi labour force where only (14%) of the labour force is female (Ministry of Economy and Planning, 2005-9: 327).

Personal monthly income and source of income
An overwhelming majority of respondents (92%) reported not having any personal monthly income or less than 500SR (£ 0-68) and only (8%) reported having any personal monthly income. Although the questionnaire inquired about 'salary', the respondents reported that the source for this income was actually in the form of 'retirement' benefits on health grounds (5%) and (3%) from social security. It must be noted that a very small percentage of women received inheritance (2%). From the very small percentage that had any personal income only (4%) reported receiving between 500-3999SR (£69-542) and (2%) received 4000SR or more; (2%) did not give a specific amount of income; instead reported that it varied from month to month.

Household monthly income and source of income
Household monthly income is based on the salary of the head of the household and is spent on family necessities, over which the respondents had no independent control. The table reveals that the respondents' source of income depended on who was the head of household and legal guardian. Although the questionnaire included female relatives under the category of source of income, the head of the household/legal guardian for all respondents was male. Overall, (41%) of respondents received financial support from their husband; (17%) from a son; (15%) from their father; (4%) from a brother; and (1%) from relatives.

As to the household income, (20%) of the respondents did not know how much the head of the household earned; (23%) reported that the amount of income varied from month to month; and (3%) reported that there was no income at all. These statistics indicate that these respondents' household income was erratic at best and non-existent at worst. The household income for (26%) of respondents was between 500-3999SR, for (14%) of the respondents was between 4000-4999SR (£543-677); and for only (13%) was 5000SR or more. It is important to note that while asking questions concerning income, all respondents commented on their family's financial difficulties and how their illness placed greater burden on family resources.
### Table 5.1
Demographic profile of all women undergoing haemodialysis at JKC

<table>
<thead>
<tr>
<th>Category</th>
<th>( n )</th>
<th>Column %</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Nationality</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Saudi</td>
<td>200</td>
<td>93</td>
</tr>
<tr>
<td>Non-Saudi</td>
<td>16</td>
<td>7</td>
</tr>
<tr>
<td><strong>Age</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt; 24 years</td>
<td>24</td>
<td>11</td>
</tr>
<tr>
<td>24-35</td>
<td>36</td>
<td>17</td>
</tr>
<tr>
<td>36-59</td>
<td>118</td>
<td>55</td>
</tr>
<tr>
<td>60 and over</td>
<td>38</td>
<td>17</td>
</tr>
<tr>
<td><strong>Marital status</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Single</td>
<td>37</td>
<td>17</td>
</tr>
<tr>
<td>Married</td>
<td>112</td>
<td>52</td>
</tr>
<tr>
<td>Separated</td>
<td>6</td>
<td>3</td>
</tr>
<tr>
<td>Divorced</td>
<td>15</td>
<td>7</td>
</tr>
<tr>
<td>Widow</td>
<td>46</td>
<td>21</td>
</tr>
<tr>
<td><strong>Number of children</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No children</td>
<td>7</td>
<td>4</td>
</tr>
<tr>
<td>1-3</td>
<td>41</td>
<td>24</td>
</tr>
<tr>
<td>4-6</td>
<td>75</td>
<td>43</td>
</tr>
<tr>
<td>7 or more</td>
<td>50</td>
<td>29</td>
</tr>
<tr>
<td><strong>Educational level</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Can't read or write</td>
<td>146</td>
<td>68</td>
</tr>
<tr>
<td>Can read and write</td>
<td>18</td>
<td>8</td>
</tr>
<tr>
<td>Elementary</td>
<td>14</td>
<td>7</td>
</tr>
<tr>
<td>Intermediate</td>
<td>14</td>
<td>7</td>
</tr>
<tr>
<td>Secondary</td>
<td>16</td>
<td>7</td>
</tr>
<tr>
<td>College</td>
<td>8</td>
<td>3</td>
</tr>
<tr>
<td><strong>Employment status</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>206</td>
<td>95</td>
</tr>
<tr>
<td>Yes</td>
<td>10</td>
<td>5</td>
</tr>
<tr>
<td><strong>Personal monthly income</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No income or &lt;500SR (£0-68)</td>
<td>199</td>
<td>92</td>
</tr>
<tr>
<td>500-999SR (£69-135)</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>1000-1999</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>2000-3999</td>
<td>4</td>
<td>2</td>
</tr>
<tr>
<td>4000 or more</td>
<td>4</td>
<td>2</td>
</tr>
<tr>
<td>Varies from one month to another</td>
<td>5</td>
<td>2</td>
</tr>
<tr>
<td><strong>Source of personal monthly income</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>None</td>
<td>196</td>
<td>91</td>
</tr>
<tr>
<td>Salary (retirement benefits on health grounds)</td>
<td>10</td>
<td>5</td>
</tr>
<tr>
<td>Inheritance</td>
<td>4</td>
<td>2</td>
</tr>
<tr>
<td>Social security</td>
<td>6</td>
<td>3</td>
</tr>
</tbody>
</table>
### Household monthly income

<table>
<thead>
<tr>
<th>Income Level</th>
<th>Number</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>No income</td>
<td>7</td>
<td>3</td>
</tr>
<tr>
<td>Don't know</td>
<td>43</td>
<td>20</td>
</tr>
<tr>
<td>Less than 500SR (£68)</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>500-999</td>
<td>3</td>
<td>1</td>
</tr>
<tr>
<td>1000-1999</td>
<td>17</td>
<td>8</td>
</tr>
<tr>
<td>2000-2999</td>
<td>15</td>
<td>7</td>
</tr>
<tr>
<td>3000-3999</td>
<td>20</td>
<td>9</td>
</tr>
<tr>
<td>4000-4999</td>
<td>31</td>
<td>14</td>
</tr>
<tr>
<td>5000 or more</td>
<td>29</td>
<td>13</td>
</tr>
<tr>
<td>Varies from one month to another</td>
<td>50</td>
<td>23</td>
</tr>
</tbody>
</table>

### Source of household monthly income

<table>
<thead>
<tr>
<th>Source</th>
<th>Number</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Father/Mother</td>
<td>33</td>
<td>15</td>
</tr>
<tr>
<td>Husband</td>
<td>88</td>
<td>41</td>
</tr>
<tr>
<td>Brother/Sister</td>
<td>9</td>
<td>4</td>
</tr>
<tr>
<td>Son/Daughter</td>
<td>39</td>
<td>17</td>
</tr>
<tr>
<td>Relatives</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Varies from one month to another</td>
<td>26</td>
<td>12</td>
</tr>
</tbody>
</table>

### Accommodation type

<table>
<thead>
<tr>
<th>Type</th>
<th>Number</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Apartment</td>
<td>102</td>
<td>47</td>
</tr>
<tr>
<td>Villa</td>
<td>13</td>
<td>6</td>
</tr>
<tr>
<td>Folk home (Shack)</td>
<td>99</td>
<td>46</td>
</tr>
<tr>
<td>Other</td>
<td>2</td>
<td>1</td>
</tr>
</tbody>
</table>

### Number of rooms

<table>
<thead>
<tr>
<th>Rooms</th>
<th>Number</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>1-3</td>
<td>68</td>
<td>32</td>
</tr>
<tr>
<td>4-6</td>
<td>130</td>
<td>60</td>
</tr>
<tr>
<td>More than 7</td>
<td>18</td>
<td>8</td>
</tr>
</tbody>
</table>

### Form of payment for accommodation

<table>
<thead>
<tr>
<th>Payment</th>
<th>Number</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Rent</td>
<td>132</td>
<td>61</td>
</tr>
<tr>
<td>Owned</td>
<td>81</td>
<td>38</td>
</tr>
<tr>
<td>Donation</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Other</td>
<td>2</td>
<td>1</td>
</tr>
</tbody>
</table>

### Estimated travel time from home to JKC

<table>
<thead>
<tr>
<th>Time</th>
<th>Number</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt; 20 minutes</td>
<td>9</td>
<td>4</td>
</tr>
<tr>
<td>20-59 minutes</td>
<td>161</td>
<td>75</td>
</tr>
<tr>
<td>One hour to less than two hours</td>
<td>36</td>
<td>17</td>
</tr>
<tr>
<td>Two hours or more</td>
<td>10</td>
<td>4</td>
</tr>
</tbody>
</table>

### Means of transportation to JKC

<table>
<thead>
<tr>
<th>Transportation</th>
<th>Number</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Own Car/ driver</td>
<td>24</td>
<td>11</td>
</tr>
<tr>
<td>Father's car</td>
<td>16</td>
<td>7</td>
</tr>
<tr>
<td>Husband's car</td>
<td>45</td>
<td>21</td>
</tr>
<tr>
<td>Brother's car</td>
<td>20</td>
<td>9</td>
</tr>
<tr>
<td>Son's car</td>
<td>48</td>
<td>3</td>
</tr>
<tr>
<td>Other relative's car</td>
<td>3</td>
<td>22</td>
</tr>
<tr>
<td>Friend / neighbour's car</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>Taxi</td>
<td>40</td>
<td>19</td>
</tr>
<tr>
<td>Varies every time</td>
<td>18</td>
<td>8</td>
</tr>
</tbody>
</table>

n=216 100%
Accommodation type, number of rooms and form of payment

Table 5.1 shows that the percentage of respondents living in apartments (47%) and those living in folk homes (46%) are practically equal. Folk homes are traditional homes that may be no larger than a 4-room apartment. The main distinction between these two types of dwellings is that the rooms of a folk home overlook an enclosed courtyard. A small percentage lived in villas (6%) which are similar to English-style townhouses. The housing for the vast majority (60%) of respondents has 4-6 rooms; (32%) has 1-3 rooms; and only (8%) live in housing with more than 7 rooms. The majority of respondents complained of living in crowded accommodation where there was little or no privacy for individual family members. The majority of respondents lived in rented homes (61%) as opposed to owned homes (38%). The respondents who came to own their home inherited it from their father. A small minority of respondents (1%) received donations in the form of free housing.

Estimated travel time from home to JKC

An overwhelming majority (75%) of respondents lived between 20-59 minutes travel time from the JKC, while (4%) lived two hours or more away. Travel time for (17%) was between one to less than two hours; and for only (4%) was less than 20 minutes. One must be mindful that these statistics do not account for roundtrip travel time, number of visits per week, or time spent waiting to be picked up from or dropped at the JKC.

Means of transportation to JKC

Table 5.1 indicates that most of the respondents depended on their husband's car (21%) or son's car (3%) for transportation to the JKC; while a close third used a taxi (19%). Although the questionnaire joined taxi and bus in this category, these respondents only used taxi service. They reported that the bus was too inconvenient or unavailable in their area. In addition, (7%) used their father's car, 9% used a brother's car, (11%) used their own car with a driver, (22%) used other relative's car, and only (1%) used a friend/neighbor's car, with (8%) indicating that their means of transportation varied every time depending on the availability of a male driver. These statistics conform to the Saudi custom that only men are allowed to drive.

Table 5.2 provides information on haemodialysis of all women with ESRF.

Haemodialysis information

Table 5.2 provides information on haemodialysis of all women with ESRF. The largest category of women, (43%) received their first HD session immediately after diagnosis, whereas, the remaining women were placed on medication for a period of time before receiving their first HD session. However, a small percentage of women received HD less than 8-11 months after medication (16%), (39%) of the remaining women did not receive HD until 1-6 years after they were on medication, and (2%) received HD after six years. It can be inferred from this data that the largest category of women were already in end stage renal failure by the time they first visited the doctor and therefore had to be immediately placed on dialysis.
Table 5.2
Haemodialysis information for all women undergoing haemodialysis (HD) at JKC

<table>
<thead>
<tr>
<th>Time between diagnosis and HD</th>
<th>n=</th>
<th>Column %</th>
</tr>
</thead>
<tbody>
<tr>
<td>Immediately after diagnosis</td>
<td>92</td>
<td>43</td>
</tr>
<tr>
<td>Less than 8 months after</td>
<td>29</td>
<td>13</td>
</tr>
<tr>
<td>9-11 months</td>
<td>7</td>
<td>3</td>
</tr>
<tr>
<td>1-3 years</td>
<td>71</td>
<td>33</td>
</tr>
<tr>
<td>4-6 years</td>
<td>13</td>
<td>6</td>
</tr>
<tr>
<td>More than 6 years</td>
<td>4</td>
<td>2</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Number of years on HD</th>
<th>n=</th>
<th>Column %</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt; 6 months</td>
<td>12</td>
<td>6</td>
</tr>
<tr>
<td>6&lt;12 months</td>
<td>9</td>
<td>4</td>
</tr>
<tr>
<td>1-3 years</td>
<td>58</td>
<td>27</td>
</tr>
<tr>
<td>4-6 years</td>
<td>48</td>
<td>22</td>
</tr>
<tr>
<td>More than 6 years</td>
<td>89</td>
<td>41</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Number of times receiving HD</th>
<th>n=</th>
<th>Column %</th>
</tr>
</thead>
<tbody>
<tr>
<td>Three times a week</td>
<td>178</td>
<td>82</td>
</tr>
<tr>
<td>Two times a week</td>
<td>36</td>
<td>17</td>
</tr>
<tr>
<td>Once a week</td>
<td>2</td>
<td>1</td>
</tr>
</tbody>
</table>

The majority of women (63%) had been on dialysis for more than four years; whereas, the least number (10%) were on dialysis for less than 11 months, and (30%) had been on dialysis from 1-3 years. An overwhelming majority of women (82%) received HD three times a week, (17%) twice a week, and only (1%) once a week. This data indicates that most of the participants were in urgent medical condition.

Table 5.3 shows an association between the household composition of all women undergoing haemodialysis and marital status. The household composition of women undergoing haemodialysis is strongly related to their marital status. None of the respondents lived alone, which according to Saudi tradition requires all women, regardless of marital status, to live with a male legal guardian.

The only household composition for single women consisted of living with their parents and siblings (65%); or parents, siblings and extended family (35%). This data reflects the traditional lifestyle for single Saudi women. The majority of married women (67%) lived with their husband and offspring; and (23%) with husband, offspring, and extended family member(s), and/or in-law(s). The remaining (10%) lived with their husband only, or offspring only, or extended family only.
Table 5.3
Household composition of women undergoing haemodialysis according to marital status (N=216)

<table>
<thead>
<tr>
<th>Household composition</th>
<th>Marital status</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Single</td>
</tr>
<tr>
<td>Lives alone</td>
<td>0</td>
</tr>
<tr>
<td>With parents and siblings (immediate/nuclear)</td>
<td>65</td>
</tr>
<tr>
<td>Parents, siblings and one or more extended family member</td>
<td>35</td>
</tr>
<tr>
<td>Husband only</td>
<td>0</td>
</tr>
<tr>
<td>Husband and offspring</td>
<td>0</td>
</tr>
<tr>
<td>Husband, offspring and one or more extended family member; and/or in-law</td>
<td>0</td>
</tr>
<tr>
<td>Offspring only</td>
<td>0</td>
</tr>
<tr>
<td>Offspring and one or more extended family member</td>
<td>0</td>
</tr>
<tr>
<td>Extended family only</td>
<td>0</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>(100%)</th>
<th>(17%)</th>
<th>52%</th>
<th>(3%)</th>
<th>(7%)</th>
<th>(21%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>n=216</td>
<td>37</td>
<td>112</td>
<td>6</td>
<td>5</td>
<td>46</td>
</tr>
</tbody>
</table>

For key family relationships of women within Saudi family structure see Figure 4.1.

All of the women who were separated but still legally married, the vast majority of divorced women (73%), and half of the widowed women (48%) lived with their offspring and one or more extended family members. After these women moved out of their husband's home, they moved in with a legal guardian (e.g., grandfather, uncle) who took the place of a deceased father or unavailable brother. This data conforms to the tradition that requires women who no longer live with their husband to move in with a male legal guardian. Equal proportions of divorced women lived with their offspring only (13%) or extended family only (13%); whereas more widows (41%) of widowed women living with their offspring and (11%) with extended family. The higher percentage of widowed women lived with their offspring as opposed to their divorced counterparts was because the former could stay in their home because they either inherited the home or they had a son over 16 years of age; while the latter had to move out because their ex-husband was no longer their legal guardian.

In addition to describing the socio-demographic characteristics of women undergoing haemodialysis, I examined their perception regarding their health condition and the extent it affected their position within the family (Appendix D, section IV, questions 2 and 3). Table 5.4 shows the extent of physical and psychological interference of HD on social roles and social relationships. In the questionnaire, 'extent' was described in four categories: not at all, slightly, moderately, and extremely. The data represented in this table complements the conceptual issues concerning the impact that ESRF has on chronically ill women and their social roles and relationships that is examined in subsequent chapters.
Table 5.4
Extent of physical and psychological interference due to HD on (a) social roles and (b) social relationships

<table>
<thead>
<tr>
<th></th>
<th>Not at all</th>
<th>Slightly</th>
<th>Moderately</th>
<th>Extremely</th>
<th>% col.</th>
</tr>
</thead>
<tbody>
<tr>
<td>(a) Social roles</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Physical problems</td>
<td>1</td>
<td>1</td>
<td>38</td>
<td>61</td>
<td>100</td>
</tr>
<tr>
<td>Psychological problems</td>
<td>1</td>
<td>1</td>
<td>38</td>
<td>61</td>
<td>100</td>
</tr>
<tr>
<td>(b) Social relationships</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Physical problems</td>
<td>6</td>
<td>13</td>
<td>38</td>
<td>43</td>
<td>100</td>
</tr>
<tr>
<td>Psychological problems</td>
<td>6</td>
<td>13</td>
<td>38</td>
<td>43</td>
<td>100</td>
</tr>
</tbody>
</table>

Table 5.4 (a) reveals that the majority of women (61%), perceived their physical and psychological problems due to HD to 'extremely' interfere with their social roles; while (38%) of the women perceived them to 'moderately' interfere with their roles, while the remaining (2%) perceived interference to be 'slightly' or 'not at all'.

The largest percentage of women (43%), perceived their physical and psychological problems to 'extremely' interfere with their social relationships (Table 5.4 (b). (38%) of the women perceived them to 'moderately' interfere with their relationships, (13%) perceived interference to be 'slightly', and (6%) perceived interference to be 'not at all'.

It is interesting to note that the respondents indicated that their physical and psychological problems were equally responsible for interfering with their social roles and social relationships. This data implies that they found their psychological problems to be just as significant to their life as their physical ones.

Conclusion

Since there was no available data regarding Saudi women with ESRF, I conducted a quantitative survey to obtain a socio-demographic profile of all women undergoing haemodialysis at the Jeddah Kidney Centre (JKC) over a period of three months. A survey questionnaire was utilized to collect information concerning their personal background and medical condition, which also provided background data to set the ground work for my qualitative study.

Data revealed the serious status of the respondents' medical condition. The majority of women (63%) had been on dialysis for more than four years, with only (10%) on dialysis for less than 12 months. The vast majority (82%) received HD three times a week.
Age, marital status and motherhood are important variables that underpin the status of women according to the Saudi gender based social structure. The majority of survey respondents were midlife women between 36-59 years (55%) while the lowest percentages of women were less than 24 years of age (11%). The majority of respondents were married (52%), the previously married respondents constituted (31%), and the remaining (17%) were single.

The data regarding educational level and employment status reveals that an overwhelming majority of these women were illiterate (68%) and had never been employed (95%). In consequence, (92%) of these women did not have any personal income and had to rely entirely upon their male legal guardian for household monthly income.

The household composition of women undergoing haemodialysis was strongly associated with their marital status. All of the single women lived with their parents and siblings and/or extended family. The majority of married women lived with their husband and offspring (90%), among which (23%) included parents, siblings and extended family in their household. The remaining (10%) lived with their husband only, offspring only, or extended family only. With the exception of the 41% of widowed women who lived only with their offspring, most of the previously married women had to move into a household with a male legal guardian - after separation (100%), divorce (86%) and widowhood (59%).

This profile of socio-demographics, haemodialysis information and household composition of women undergoing haemodialysis provided insight into the socio-economic aspects of their everyday life.
Chapter Six
Qualitative Research Design

In order to have a clear conceptual understanding of the impact of end-stage renal failure on the everyday life of Saudi women, it was necessary to use a qualitative research design. The in-depth interview is the most appropriate design for my study because it is flexible and adaptable by nature. This research design also enabled me to obtain valuable detailed information and knowledge of these women's attitudes, ideas and thoughts as they expressed themselves in their own words.

Unlike designing quantitative research, the design of qualitative research cannot be wholly prepared in advance as a 'blueprint' document on account of the nature of qualitative research itself. 'This is because qualitative research is characteristically exploratory, fluid and flexible, data-driven and context-sensitive' (Mason, 2002: 24). Thus, it lends itself to the particular nature of the data generated that aids in understanding and interpreting Saudi women's illness and disability experiences with chronic renal failure. Although Mason contends that advance blueprints do not befit qualitative research design, she does assert that it is necessary for a researcher to produce a research design at the inception of the process, stating that 'the main proviso is that thinking about strategy and design should not stop there' (p. 24). In line with Mason, my qualitative design and strategy began when I formulated the primary aim of the research: to explore the impact of ESRF on the everyday life of Saudi women.

The rationale for using qualitative interviews

The qualitative method that was used in my study included unstructured in-depth interviews that allowed me to obtain personal details from the participants in their own words. Lofland (1971), states the objective of this type of interview is 'to elicit rich, detailed materials that can be used in qualitative analysis...to find out what kinds of things are happening...' (p. 76). By utilizing this method, I was able to gain a better insight into their illness experience.

The flexibility and adaptability of in-depth interviews will enabled me to have a clear conceptual understanding of the impact of end-stage renal failure on the everyday life of Saudi women. While qualitative interviews allowed the participants to freely express themselves, they also allowed me to adapt the interview to the participants' level of comprehension and articulacy (Fielding and Thomas, 2001: 124). Also, unstructured interviews will likely be the most effective method of obtaining responses from women who are 'semi-literate, frail, and suspicious'(p. 125).

Using qualitative interviews also allowed the 'interviewers to take their own path within certain guidelines' (Fielding and Thomas, 2001: 124), while allowing them to explore sensitive issues that pertain to participants' life that may normally embarrass them when asked in closed question format (Edwards, 1993). Furthermore, this approach enabled me to investigate underlying meanings and to better understand these women's subjective reality, including the complexities and variations of their experiences and their perceptions of those experiences. I used prompting, which 'involves encouraging the respondent to produce an answer' and
neutral probing that 'involves follow-up questioning to get a fuller response' (Fielding and Thomas, 2001: 128) to elicit additional information that may have been needed for clarification or elaboration. In these ways many underlying issues relating to these women's struggles will be revealed and will better equip social scientists, policy makers and health care providers to improve and broaden the scope of research, community services, and health care.

Importantly, qualitative interviews helped me establish the necessary rapport with the participants because they were allowed to share their own experiences without the confines of a structured format. These interviews were conducted using an interview guide (Appendix E translated English version; Appendix E(i) original Arabic version) that included topics regarding demographic information, medical history, affect of ESRD and haemodialysis on their physical; emotional; and social well-being; etc. The purpose of this guide was to assist me in maintaining focus on these specific topics while enabling the participants to describe and reflect on their own illness experience.

This chapter discusses the qualitative research design, rationale for using qualitative interviews, aim of the study and research questions. It includes discussion of the sample for the study, ethical issues, the pilot study, conducting repeated interviews, and issues related to the sensitivity of the subject. A demographic profile of the Saudi women who were interviewed is also included.

**Aim of the study and research questions**

The aim of this study is to examine the impact that end stage renal failure (ESRF) and haemodialysis (HD) has on the lives of Saudi women. Specifically, this study explores gender-related issues that affect the various aspects of chronically ill and disabled women's life. This study will examine the impact ESRF has on their quality of life, perceptions of themselves and their illness (body image, self-concept and identity) that may prove to be detrimental to their family care-giving roles and relationships, and how they manage their everyday life. Although these concepts are highlighted in western sociological literature, this study critically re-evaluates them in the light of the socio-cultural differences found in Saudi society.

The research questions explored in this study are:

- How do gender-related issues and structural barriers of Saudi society disable chronically ill Saudi women?
- To what extent does ESRF disrupt the family care-giving roles and relationships of Saudi women and affect the quality of life?
- In what ways do Saudi women's perceptions of themselves and their illness affect their abilities to manage and adjust to their new way of life with ESRF?
Sample

In Phase I (see Chapter 5) a complete socio-demographic census of all 216 women undergoing haemodialysis was taken. From these 216 women, all non-Saudi women and all Saudi women under the age of 24 years and over the age of 59 years were excluded from the sampling frame. The sampling frame therefore included 150 Saudi women between the ages of 24-59 years. They comprise the 'list of the members of the population under investigation and is used to select the sample' (Arber, 2001: 60) for in-depth interviews.

The Phase II sample will comprise of 50 Saudi women undergoing haemodialysis between the ages of 24-59 years old. Participants in this age group are chosen because they are at the peak of their childbearing and childrearing years and are more likely to be wives and mothers. As indicated in Chapter 4, Saudi women marry at a young age and the fertility rate is high. Since marital and parental roles are seen as the most pivotal ones played by women in Saudi society, this is a very important age group for my study. There is a greater likelihood that those over 40 years old will have older children and/or even grandchildren. A 'systematic selection' sample will be chosen from the sampling frame where 'all elements of the population are listed and a fixed sampling interval is used to select the sample members' (Arber, 2001: 68). I choose this method because of its advantage of obtaining sample participants from this list 'that are more likely to be more evenly spread across the population' (p. 69). The sampling interval that was chosen for the interviews is number three. This means that the occupant of every third bed in the HD unit according to the shift schedule was selected for the in-depth interviews.

I am aware that when a study population conforms to a particular list, such as that compiled from Phase I, 'it is essential to consider how restricting the sample may influence the conclusions that are drawn...The researchers should recognize the constraints on interpretation which arise from their method of sampling...' (Arber, 2001: 63). I, therefore acknowledge that the research questions I addressed in my study were influenced by the socio-economic characteristics of the study population. Since JKC is a government-subsidized medical facility that provides free services to its patients, I expect that the highest percentage of women with ESRF undergoing dialysis will fall into the low socio-economic status groups.

Ethical issues in qualitative research

Although ethical issues discussed in Chapter Five with regards to obtaining informed consent, confidentiality and anonymity remain crucial throughout the interview process, additional issues arose relating to the need to ask sensitive questions and tape recording interview sessions.

The question of whether or not to disclose the specific research aims to the participants at the initial stages of the interviewing process had been raised by researchers in the field of qualitative methods. While some hold the view that participants should be informed of the aims of the research at the outset of the interview (Oppenheim, 1992; Rubin and Rubin, 1995), others argue that this
should be avoided so as not to influence the participants who may unintentionally tailor their responses to suit the researcher's aims (Edwards, 1993).

Although I understood Edward's rationale, I found it ethically necessary to inform the participants of my research goals in the letter of introduction (Appendix B) in order to help them decide whether or not to give their consent (Appendix C) to participate in my study. More importantly, they needed to know not only why I was conducting the study but the topics that I would address so that they could relay this information to either their fathers or husbands. I was already aware of this necessity because of the Saudi socio-cultural norms that require that women of all ages obtain the consent of their male legal guardian before any personal decisions can be made by them. Even though I had previously received verbal consents from the participants for interviewing them at the JKC, it was crucial for some of the patients to also obtain approval from their male guardians regarding the subsequent interviews that would take place in their home.

Since the issues to be discussed were personal and sensitive in nature, especially in a conservative society where private matters concerning the family are not discussed outside the family network, it is important to note that the participants were neither subjected nor exposed to any mental harm. I learned early on in my study that regardless of how careful and sensitive I was to the needs of the participants, the stress that may be experienced on the part of both the interviewer and the interviewees is a natural side-effect of the in-depth interview (Brannen, 1988: 552). So, I never pressured them to pursue topics that caused them emotional distress. In addition, I tried to avoid causing participants any physical harm or discomfort. I was always mindful of their medical condition when scheduling appointments, and paused during interviews so that participants could regain their composure and energy.

Though the participants refused to be tape recorded during the pilot study, all participants eventually agreed during the second interviews. I attribute their change of mind to my attempts at establishing a rapport with them and gaining their trust before the actual interview; especially during the first interviews when by word of mouth, the participants influenced each other's decision to agree to tape record the interviews. In order to get the participants accustomed to the tape recording, I saw them several times at the dialysis centre. During these first interviews, I stopped the tape recorder and informally conversed with them; constantly reminding them of the main purpose of my research. Even though I had their consent to tape record, I stopped the tape recorder during the interview when they indicated that they did not want to continue tape recording a particular topic.

Pseudonyms were used to protect the participants throughout the process to ensure that the participants are not identified by name or description under any circumstances, including any future publication of the results.
Piloting the qualitative interviews

The main purposes for conducting a pilot study are to assess and analyse the significance of the issues relating to the nature and scope of the impact of chronic illness and disability on Saudi women with ESRF. During August–November 2003, the first phase of the pilot study comprised 11 in-depth interviews, drawn from one hospital and two medical centres subsidized by MOH that services different parts of Jeddah. All the women were between the ages of 24-51 years old, with varying marital statuses (6 were married, 2 were divorced, 2 single, 1 widow), with and without children, differing educational and income levels, as well as family structure. Four interviews were conducted at the medical sites and seven at JKC. These interviews lasted for about 40 minutes to an hour. Although they originally were to take place in the social worker's office or the conference room located in the same unit, at the request of the patient several interviews were conducted during their dialysis session since they were available for those 4 hours. None of the interviews were tape recorded because of their suspicion about the use of personal information elicited during the interviews. As an alternative to taping, I tried to use the help of an assistant to take shorthand notes. Although this arrangement was agreed upon at the time the appointment was set, patients were reluctant to share their experiences within the presence of another person. I made a note in my journal not to bring another individual with me to the interviews and to try again to encourage them of the need for using the tape recorder during the sessions.

It should be noted that hesitation and suspicion on the part of the participants has to be considered within the context of Saudi socio-cultural norms. Saudi women do not divulge their private matters to strangers and are expected by family members, especially their husband, not to reveal information that may prove to be embarrassing to the family. Furthermore, they are unaccustomed to any interview process since there are rarely any occasions for it. Thus, it is completely outside their realm of understanding to tape record their conversations.

During the pilot interviews, I imposed no constraints on the women in terms of issues relating to their illness experience that they wanted to discuss. I tested the interview guide to determine how they would respond to various topics. During the interviews, I gave them plenty of time to share their experiences. I also took brief notes, which I then referred to for clarification or elaboration. I made a conscious effort not to interrupt their responses and disrupt their flow of thoughts and only probed where clarifications were needed. However, I noticed that I had to resort to asking leading questions in order to elicit relevant information because they found it difficult to respond to open-ended ones. This meant that I ended up asking many more questions in each interview than I had anticipated. Throughout the entire piloting process, I had to constantly employ listening skills so as not to miss any relevant information.

I encountered many disruptions during these interviews, e.g., nurses checking the patient's dialysis process, which that led me to conclude that I could not efficiently conduct thorough interviews at the medical facility. I made another note in my journal to consider alternative sites for interviewing.
The second phase of the pilot study (December 2003) included 8 in-depth interviews to test the refined format of the in-depth interview guide. Unlike the first pilot study, this one only included participants from the JKC from all four shifts (7a.m to 11p.m). Each of these women was separately interviewed for an hour at the JKC. They were between the ages of 24-57 years old, varying in marital status (6 were married, 2 were divorced) with and without children, differing educational and income levels, as well as family structure. However, they were similar to the first pilot study in that all of them refused tape recording so I had to resort to taking notes.

I noted in my journal that there was an urgent need to conduct repeated interviews in order to obtain more detailed relevant data. The need for repeated interviews stemmed from the difficulties I faced during the pilot study when many disruptions coupled with the distraction of copious note-taking impeded my ability to get a complete picture of each participant's life in relation to her chronic illness and disability.

**Interviewing female medical and nursing practitioners**

While I was at JKC piloting the interviews with the participants, I found it helpful to also interview a number of female medical and nursing staff at the dialysis centre. They expressed interest in my research because they saw the connection between the issues raised in my study and those encountered by their patients on a daily basis. Later, I set appointments with them and was able to engage in further discussions in the conference room. These practitioners were key informants who gave me invaluable background information on the participants and their conditions because they had been treating them at the JKC for many years. They helped to clarify questions concerning various medical aspects of the symptoms, diagnosis and treatment. They also informed me of other personal issues that concerned the participants which I noted for later use when interviewing the participants. Overall, the information I received from these practitioners helped to compensate for the lack of literature on chronically ill Saudi women. These interviews took the form of informal discussions which I tape recorded.

**Conducting repeated in-depth interviews**

The rationale for conducting repeated interviews with women living with ESRF primarily has to do with difficulties encountered during the pilot study. In order to encourage participants to share all aspects of their illness experience with me, I realized that I had to arrange for a comfortable environment and establish rapport. I decided that two sets of in-depth interviews with all participants would also be necessary to rekindle their numerous memories (Lee and Renzetti, 1993). It is important to note that many of the participants had been under dialysis for many years, so they had to think back and try to recall how they felt at the beginning stages of their diagnosis and treatment. Thus, repeated interviews were crucial to allow them to sift through all their past feelings that had occurred over such a long period of time. Otherwise, their immediate responses would more likely have reflected how they felt during the most recent period of illness.
These repeated interviews were conducted between July 2004 and July 2005. All participants were interviewed twice, which is referred to as the 'first set' and the 'second set' of interviews in this study. Conducting two sets of interviews for each participant allowed me to seek further clarification and make necessary adjustments to any issues that may have been originally muddled in their minds during the first interview. Participants were able to use the one to three weeks between the first and second interviews to reflect upon their experiences, so that by the time we met again they were able to provide me with a clearer depiction of prior events.

Each of these interviews lasted approximately 1 to 4 hours, depending either on the condition of the participant at the time of the interview, or on the interruptions, clarifications, willingness to talk; and attitudes, such as shyness, general reluctance to divulge personal information which resulted in anxiety and fear in exposing their intimate feelings. Despite my concern for interrupting the rhythm of the participants' narratives, I had to adjust to practical considerations, such as reviewing, comparing and noting discrepancies in previous statements. Therefore, I had to establish a delicate balance between safeguarding the mood of the interviews and the obtaining of accurate data. All interviews were conducted in the Arabic language.

Structure of first interviews

The main goal of the first interviews was to establish a rapport with the participants and gain their trust. I did not expect to collect an enormous amount of information at this stage. I was only laying the foundation for the second interviews where I hoped that they would subsequently open up to me and disclose more personal and intimate details of their illness experience.

I used the unstructured in-depth interview with an interview guide (Appendix E) whose primary purpose is to explore the extent of certain issues concerning: demographic information, medical history, effect of ESRD and haemodialysis on their overall experience of living with a long-term chronic illness and disability. The interview guide sheet included research issues to be addressed. The number and the order of these questions varied depending on each participant. These questions were designed to elicit narrative responses concerning their personal thoughts about their illness, underlying medical problems that accompany their condition, their way of life before and after diagnosis, and the changes that occurred in their lives due to illness and the treatment therapy. The discussion also covered issues relating to managing their life with ESRF. Any additional factors that they felt were important were also included. I encouraged them to express themselves freely in their own words, thereby eliciting the 'meaning' of their illness experience.

Location and time of first interviews

During the first interviews, I gave the participants the opportunity to choose the location and time of their interviews. All the participants chose to be interviewed in the conference room at the JKC. The participants were usually alone during these interviews, but sometimes a relative, i.e., daughter or a close female relative or friend was present. The majority of them chose to be interviewed on the same
day as their dialysis treatment session, since they were already at the dialysis centre and each haemodialysis session lasted 4 hours. Some chose to be interviewed prior to their session while others chose to be interviewed after the session. I declined the choice to conduct interviews during dialysis because of my prior experiences during the pilot study. It was then that I realized that the commotion from the machines and traffic from the medical personnel, along with the lack of space and privacy was a great impediment to the interview process.

Even though the participants chose their own interview times, the rate of participation was still inconsistent. Many of the participants missed their interviews using medical or personal reasons as excuses. Either they cancelled in person or left messages with the nurses. So, I had to set up new appointments based on their dialysis schedule and my interviewing schedule.

Logistical problems of first interviews

During the first interviews, I introduced the use of the tape recorder. After all the accommodations I made to ease their minds, I still had to emphasize the practical use of tape recorders in maintaining accurate records and transcription. Yet, at this stage, only 4 participants who were eager to engage in conversation agreed to be tape recorded. The other participants were reserved at this initial stage of the interview process.

Another logistical problem I faced during this stage of these interviews was my being confronted with the different dialects spoken within the Saudi Arabic language. Although both participants and I spoke the same language, when it came to expressing their personal thoughts and intimate feelings, the participants resorted to using their indigenous dialects, which vary from Bedouin, rural or urban regions. So, I had to clarify their responses and make notes of the unfamiliar words and their meanings. Whenever words needed further clarification, we resorted to using classical Arabic.

The first interviews with the participants proved to be of great importance to me because I was able to gain better insight into their varied personalities. I attempted to establish what Oakley (1993: 24) refers to as a 'sympathetic relationship' with the participants, keeping in mind the various skills needed to facilitate the interview process: listening intently to their responses, noting their mood-changes, and observing their body language. Once I got a sense of what topics they each considered to be off-limits, what areas were considered to be sensitive; which participants were more accessible, shy, or defensive, I tried to tailor my style and pace to suit their individual idiosyncrasies without alarming them. Therefore, this stage of the interview process helped me to establish a rapport with each of the participants which in turn enabled me to avoid unnecessary pitfalls that could unintentionally cause emotional and/or psychological harm.

The first interviews were conducted in one or two hour sessions to obtain factual data which included demographic information and medical history (Appendix E, Sections I and II). At this time, I did not pursue questions regarding their family care-giving roles and relationships and illness experience (Section III). There was an abundance of information being reported and to ensure I got it all down in their
own words, I asked them to repeat their answers more than once. Also, the surroundings were not conducive to hearing them clearly and there were constant interruptions, so, again I needed them to repeat their responses. The interview process grew tiresome for both the participant and me. It was at this time that I explained how the process would be easier for all concerned if they permitted it to be tape recorded. I noticed that they were not at ease at the dialysis centre and so that they would be more comfortable and in turn more forthcoming, I suggested choices for a change of venue for the next interview, i.e., coffee shop, my home or theirs. Nearly all agreed that we meet in their home and that they would consider tape recording the session.

Structure of second interviews

The primary purpose of having a two-fold approach to the interviewing process was as previously stated, to first establish a rapport with the participants; and once they were relaxed, to subsequently obtain more detailed accounts of their personal experiences in the second interview.

It was obvious that the best source of information would be elicited during the second interview because all the participants were more relaxed and forthcoming with their personal experiences after our first meeting. I feel that I was able to easily establish a rapport with the participants as one Saudi woman interviewing another Saudi woman. Some even expressed appreciation for my coming out to them and wanted to make my visit worthwhile by providing stories that they thought would reveal their experience with ESRF. To highlight particular issues, they would also offer information about a fellow-patient who had similar experiences. Once I encouraged the participants to use the narrative form of expression, I soon became aware that these interview sessions would be more time consuming which lasted on the average for 4 hours.

During the second interviews the women were more relaxed at home than at the JKC, where the first interviews took place. I believe that their relaxed state stems from Saudi socio-cultural expectations that demand a respect for privacy for both host and guest. The host expects that anything seen or heard in the home will not be reported by a guest to another person; and by accepting an invitation to visit, the guest agrees to comply. This is the reason why I felt compelled to remind them that their identity will remain anonymous and that any information they report will be used for research purposes only. They trusted that I would keep my word on these issues. They also appeared to be relaxed in their domestic setting because they were being a host who is accustomed to being hospitable to anyone who enters a home according to the dictates of Saudi socio-cultural norms. Performing the host ritual is comforting to them because they normally fulfil this role on a daily basis. For these reasons, I was able to observe that all women I interviewed at home were more open to the entire process and spoke freely on a variety of issues. In fact, they were eager to talk. They indicated that this second interview gave them the opportunity to freely express themselves for the first time, which often resulted in emotional release. Although the second interviews produced the most information, it was also the most stressful due to their outpouring of emotions. Interviews with all participants at this stage were tape recorded.
I used the same structure form of interviewing and guide that was previously used during the first interviews (Appendix E). This un-structured interview guide helped me to keep track of the topics I wanted to raise while allowing the participants to interject their personal issues. It included topics that are designed to elicit women's perception of the impact of chronic renal failure on their physical and psychosocial well-being, as well as their description of their family caregiving roles and relationships (Section III). It also explored the before and after implications of chronic illness on the participants, and assessment and comparison of the medical, physical, social and psychological changes that had taken place after the diagnosis was made, with the subsequent changes due to the haemodialysis therapy.

While conducting the interview, I had to keep in mind the various skills needed to facilitate the interview process: listening intently to the responses, noting mood-changes and observing body language of the participants. I struck a delicate balance between what was being said and the previous responses in order to detect any discrepancies. I constantly referred to the interview guide so as not to overlook any of the issues that needed to be discussed. However, it was important for me not to interrupt the rhythm of the participants, yet I still had to adjust to practical considerations when taking notes, or tape recording the sessions (Mason 1996: 46).

While I welcomed their forthcoming attitude, I became exhausted due to the long hours that resulted from their free expression. I also began to realize that a large portion of their narrative was irrelevant to my specific subject, but was unable to successfully curtail their verbosity because of the Saudi tendency to over explain, merge two stories together, or to get way off track. I therefore decided to structure the interviews into topics which helped the participants to focus on the relevant issues. Semi-structured interviews with intermittent prompting and neutral probing helped in time management.

Location and time of second interviews

The second interviews took place either at the participant's home, JKC or wherever else the participants preferred. Forty three participants decided to be interviewed in their home during the mid-morning hours. Three of the remaining seven participants were interviewed at JKC and the other four were interviewed at coffee shops that were located near JKC. I collected these participants from the dialysis centre, and afterwards I escorted them home. Out of 50 interviews, 39 were conducted on the days when there were no dialysis sessions, while the other 11 were conducted on the same day as the dialysis. During the second interviews, the attendance rate was more consistent because I personally went to their homes and any cancellations on their part would be the same as rejecting a guest, which is a social taboo in Saudi society.

Logistical problems of second interviews

A set of logistical problems arose when interviewing the women at their homes. Since women must be driven by a male driver in Saudi Arabia, many of them could not give me directions to their homes. Also, residences in the outskirts of the city do not have any consistent numbering system to identify location which
makes directions very hard to follow; and roads are often either not paved, have dead ends and/or are too narrow for vehicles to go through making driving very difficult. Since there are no postal addresses in many parts of the city, everyone refers to landmarks, i.e., next to the 'shop or behind the mosque. Even if you were to stop someone, including a policeman, he would not be able to direct you. It was therefore necessary for me with my driver to follow participants home in my own car a few days in advance of the interviews while I sketched route maps in a notebook for future reference.

Another logistical problem arose during the holy months of Ramadan [fasting] and Hajj [pilgrimage] when the entire schedule changes; resulting in two important time gaps. At this time of year, participants either leave the city for vacation (continuing their dialysis elsewhere), or entertain their out-of-town relatives. I kept in touch with participants by telephone as a reminder for them to contact me after the holidays in order to arrange the second interviews.

A third set of logistical problems arose after the holidays when I began to arrange appointments for the second interviews. It was not easy for me to arrange meetings with the participants during the early part of the day because it is not customary for Saudis to make early social calls during morning hours. Usually, appointments are scheduled after maghrib [early evening] or isha'a [late evening] prayers which fall between the hours of 6.30 to 8.55 p.m. This is why the majority of the interviews were set for the mid-morning hours when most children were presumed to be at school and their husbands, fathers and other male members were at work. So, I was surprised to discover that the participants were not alone when I arrived, because some of the children did not attend school and also some members of the extended family resided there. Thus, I found my interviews were being constantly interrupted with people coming in and going out unannounced. I soon realized that I would be unable to conduct a productive interview if I did not personally request their relatives to give us some privacy. I knew that the participant felt uncomfortable making this request and that I was in a better position, because I was there for professional reasons and not social ones.

Socio-cultural characteristics encountered during the second interviews

In order for a researcher to be an effective interviewer, she needs to familiarize herself with the religious, socio-cultural elements of Saudi customs. These include elements such as customary social interaction, verbal and non-verbal communication, the concept of time, and reluctance of participants to participate.

Sensitivity is an intrinsic characteristic of the entire qualitative interview process because the most intimate aspects of the participants' lives are being explored. It is important to keep in mind that the sensitivity of a subject is related to its social situation (Brannen, 1988). Usually a researcher's personal perception of what is actually sensitive is irrelevant. However, in my particular case, I share similar religious and socio-cultural traits with the participants, so my personal perceptions regarding what is stressful or shameful may also reflect their perceptions. I found that any topics relating to intimate issues are considered sensitive in the light of the religious and socio-cultural traits with which Saudi women are ingrained.
A face-to-face interview is much more than a research tool; it is a social encounter. It is not sufficient for the interviewer to simply rely on an interview guide; she must also be aware of the social niceties that are within the social context of the participants (Rubin and Rubin, 1995). As a Saudi, I am aware of various traits that characterize Saudi conversation. Typically, Saudis are in the habit of talking loudly, emphatically and very quickly. A conversation including Saudis is very lively and colourful. They interrupt themselves and each other with religious expressions, proverbs and exclamations. Agreements and disagreements are simultaneously made so that an outsider listening in could easily become confused. Hand gestures are frequently used to emphasize a point, which may look like the onset of an argument to a non-Saudi observer.

Another Saudi custom that is devotedly practiced among women is the 'greeting kisses', which differs in number and style depending on the region. In Jeddah, when they meet and before they depart, women shake hands and kiss each other a minimum of three times on the cheeks (once on the right side and twice on the left side). There was a different style of kissing for those participants who were from other regions, which included more than three kisses on the cheeks and/or one kiss on the forehead. Hugs are optional depending on their relationship. Even though I was basically a stranger to the participants, being a Saudi, I was expected to engage in this custom. This naturally broke down any barriers that may have existed before the meeting. It made it much easier for the participant to share personal experiences with me. She no longer viewed me as a stranger. In fact, some participants called me by the affectionate name of khallah [auntie] when they introduced me to their young children.

Since Arabic tradition dictates that the hostess serves and entertains the guests (and anything that falls short of these expectations is considered rude), the participant was constantly waiting on her guests by serving (coffee, dates, and tea) or calling someone else to do the job for her. She would never think of excusing herself because of her health condition and was always cordial despite her physical exhaustion. So, I felt it incumbent upon myself to take the responsibility of politely requesting her guests to give us some time without interruption in order to complete the interview. Even though I was there to conduct a research interview, I, too was always treated as an honoured guest and therefore had to either stop the tape recorder on numerous occasions or use hand signals to indicate that the recorder was on.

Early on in the interview process I realized that if I continued to conduct myself in an aloof and formal manner, I would fail in getting the participants to reveal their personal feelings to me. Once I allowed myself to become more friendly and informal, the dynamics of the interview changed. They began asking me questions about my family and work and wanted me to express my opinions about the questions I posed to them. However, I was always conscious of maintaining an objective perspective throughout in order to avoid bias in the data. I also had to be careful not to influence their responses when they asked for my approval of their answers or when they inquired about the other participants' answers. Assurances were made to them that there were no right or wrong answers to my questions and that these answers varied according to each participant. Many of
their responses were left dangling and incomplete, almost in the form of a 'fill in the blank'. I realized that they expected me to provide the missing word or information. This may be explained by the fact that these women were either unable to find the correct vocabulary to express themselves and/or they wanted to make sure that I understood what they meant. Their hesitancy, which characterized their responses, could also be attributed to their insecurities. Not only was the entire interview process a novelty, they doubted their suitability to be participants in such a study and often asked me if I were certain their answers would be helpful to me.

Where the above description of my interview process may appear to be slightly unusual in terms of western standards, I, as a Saudi researcher, recognize that these patterns of behaviour are traits that are prevalent in Saudi society. These women naturally expected to be able to ask me personal questions, because the session was considered more of a discussion between two women, rather than a formal interview. It would be considered rude if I refused to respond to their questions and strictly maintained a professional stance. Also, the rapport I hoped to establish would have been undermined. (Of course, it should be understood that a male researcher could never have obtained consent. One must bear in mind that the gender segregation of the sexes is always an integral part of Saudi life that can never be ignored).

Verbal and non-verbal communication

Researchers interviewing participants of any culture have to be mindful of the body language and also what may seem to be cryptic phrases or sayings of that group. Otherwise, they will miss the hidden meanings that can clarify obscure responses. As a Saudi researcher, at first I had taken the participants' gestures and signalling along with their religious phrases and stories for granted. However, after reviewing the notes made to myself during these interviews and the notes made in my journal, I realized that I had two levels of communication for each participant: the verbal level and the non-verbal level. I found that the latter form of communication was an integral part of their entire narrative, and not dispensable. The body language that accompanied their verbal responses also gave me important clues about the meanings behind what could have been normally mistaken to be mundane expressions. Examples of such body gestures include: covering their faces with their hands or head covers which indicates shyness or embarrassment; pointing a finger at their noses which indicates that they were fed up with the situation; placing their hands in a choking position around their necks which indicates that they felt suffocated or again that they had enough; or lightly hit their forehead when trying to remember something.

The body language that revealed anxiety about being overheard by others in the household included furtively looking around and turning their heads behind them. Sad thoughts were displayed when their responses came after long pauses or watery eyes. It is evident from these examples that many of the participants' true feelings would not be obvious to a researcher unfamiliar with Saudi religion and culture, because they were couched in Arabic sayings and subtle non-verbal behaviour.
Another important trait of the Saudi participants was the frequent use of Islamic phrases and traditional Arabian proverbs throughout their narrations. Typically, the participants found it difficult to cite a direct complaint or negative account to a question because they did not want to appear to be ungrateful to Allah [God]. (It is believed that complaining about one's conditions is actually criticizing Allah's will, and therefore is a grave sin). Instead, many of their responses referred to having to be patient sabr-Ayoub, [Prophet Job's patience] (a common phrase often referring to his trials and tribulations). In order to maintain peace of mind for the participants, it was absolutely necessary for both the participants and me to interject at the appropriate times such phrases as Inshallah [God willing]; Mash'Allah [God protect you] (said to protect the recipient from envy) and Alhamdullilah [thank God]. Such phrases were recited throughout the conversation and cannot be considered as irrelevant.

Concept of time

Another socio-cultural characteristic encountered during the interviewing process was the concept of time and how it is used in Saudi society. Since Muslims are required to pray five times a day at set time periods, all activities whether business or social, are arranged around the prayer schedule. Since there can be a time gap of at least two to three hours between prayers, when a participant set an appointment for example, after dhuhur [afternoon] prayer, she may interpret that to mean anytime within a three hour time frame before the next scheduled prayer. This sometimes meant that I had to wait hours before interviewing a participant, although I was at the place of interview exactly after the afternoon prayer was completed.

Reluctance of Saudi Participants

It is interesting to note the reluctance of these Saudi women to participate in research dealing with issues, such as: identity, image, women's roles and interpersonal relationships. Their reluctance may be attributed either to religious, social and/or cultural constraints. Some of them even equated the research interviews with celebrity interviews that they saw on television and did not understand why anyone would be interested in interviewing them.

Since the participants were unaccustomed to being questioned in interviews during which personal questions were being asked, the idea of being taped was a horrifying prospect. Even though the women initially agreed to its use for the second interviews, they expressed grave doubts about privacy issues. They displayed their reluctance to respond to sensitive issues by turning off the tape recorder and/or covering their mouths with their hands to stop themselves from speaking.

The women constantly needed reassurance that anonymity was guaranteed and also wanted to be certain that no personal information would be shared with others, since they were all from the same dialysis centre and knew each other over the course of their treatments. Again, I had to constantly reassure them by saying wallahi, [meaning I swear by God] (also a common cultural figure of speech), which is the only acceptable form of assurance that no one other than myself would hear their responses. At this point, it is important to emphasise the cultural
concerns addressing privacy and respect in Saudi society. Women's identity is concealed in Saudi culture by the custom of referring to married women by the first-born son's name or father's name if they have no children. Unmarried women are also referred to by their father's name. It would be considered disrespectful for a stranger to use a woman's given name, especially in a public forum. So, all married women during the conducted interviews were either referred to as Umm [mother] (the son's or father's name) or their own name if they chose. Interestingly, despite this 'built in' safeguard, a participant still was uncertain about the efficacy of this cultural safeguard when she stated that there was no such thing as absolute anonymity because her voice could still be recognized by either the participants or the staff.

Throughout my research study, I was confronted with many interesting and sometimes even surprising issues. Since these issues may be considered peculiar to Saudi society, I believe it was important to highlight them: the issues related to the sensitivity of the subject and the cultural characteristics encountered during the data collection. They may even add subtext to this study by providing a clearer picture of the obstacles that pervade this society that a researcher must be constantly aware of while conducting research in this region.

On the whole, I received positive feedback from the participants about the entire process. Despite the stressful moments they felt during the interviews, they expressed relief to have had the opportunity to share some of their innermost feelings with someone. They had felt that no one wanted to hear their miseries, and were pleasantly surprised to find that I was so concerned. As Sabra (a participant) stated:

'No one likes to hear the 'sad experiences' of someone ill... but in your case, I was surprised to know that you wanted us to talk about our experiences'. Sabra (D-M)

They were also relieved to find that they were not isolated cases but actually shared similar burdens with other women with ESRF. But there were also mixed feelings expressed by other participants. They may have agreed with the positive aspects of the interviews, yet they were also relieved when they were finished. They still harboured the fear of being identified and having their private feelings exposed to strangers. Even at this late stage of the interviewing process, I had to reassure them of the protective measures I had employed.

**Approach to data analysis**

The approach utilized to analyse my qualitative interview data was the 'grounded theory' approach, as developed by Glaser and Strauss (1967) as an analytical method for qualitative research because it 'fits empirical situations... provides us with relevant predictions, explanations, interpretations and applications' (p. 1). Such aspects include development of theoretical concepts and categories, constant comparative analysis and coding (Strauss and Corbin, 1997, 1998; Dey, 1999).

At the initial phase of the research, my aims were to explore various issues, such as self-concept and identity with regards to Saudi women diagnosed with a chronic illness. Since I was interested in the participants' personal experiences, I followed
the methodological techniques and procedures suggested by Strauss and Corbin (1998) which are viewed as essential guidelines for coding and analyzing the 'emerging' data. I used an interview guide (Appendix E) with participants and I tailored the issues according to what I observed and heard. This qualitative approach to generating and analyzing data involved use of interviews, participant observations, and field notes. The field notes included nonverbal communication and unrecorded discussions.

**Pre-coding process**

During and after each interview, I wrote brief notes in my journal to remind myself of any issues that were problematic or needed further clarification, in addition to any matters that helped to facilitate the interview process. I found it important to listen to the tapes immediately after each interview while the participants' verbal and nonverbal expressions remained fresh in my mind. In this way, I was able to visualize the events that took place during the interview as I listened to their words and expressions. As I was listening to the tapes, I wrote comments next to the participants' responses. I re-listened to the tapes at different times and made any necessary adjustments in my notes. Thus, I was able to get a better feel for the meaning and interpretation of their stories (Fielding, 1993).

Afterwards, I listened to the tapes again for the purpose of transcription. I began transcribing the tapes myself, but this proved to be very time-consuming. Then I decided to use the assistance of a typist to transcribe the interviews. The only reliable assistance I could find was an Egyptian and a Jordanian secretary. Even though their native language was Arabic, the differences in their spoken dialects and accents were problematic. They automatically exchanged unfamiliar words with their own, assuming that their meanings were the same as those of the participants. This resulted in misquotes and omissions of valuable information. Since I required the transcriptions to be verbatim, I carefully went over the transcribed tapes myself again to make sure that all the correct information was there.

After transcribing the taped interviews, I listened to them again. This time I focused on correcting any errors that had been made during the transcribing process. By re-listening to the tapes, I was also able to refresh my recollection of the interviews. Finally, I stored all the tapes in a locked cabinet at home. There were no names on the tapes to identify the participants, only case numbers that I had previously assigned to them.

While reviewing these transcribed tapes, I became more aware of the variations in the issues raised by the participants', their expressions, and their emotional responses that made coding more challenging. Since I was analyzing each transcript line-by-line and/or paragraph by paragraph I used the open coding form. Although this type of coding was more time consuming, it was particularly helpful to me in identifying concepts and categories (Strauss and Corbin, 1998).

In reviewing the interview transcripts further, I detected similar themes that crossed over from one interview to another. I then grouped the same theme from each transcript together.
The transcriptions were now scrutinized for the purpose of identifying and classifying themes. The data was sorted and grouped according to categories and sub-categories that related to their conditions, consequences, and specific relationships. As a whole, these categories and subcategories were used to develop and build an understanding of the meaning of the experience of these chronically ill women. I was then able to discern recurrent patterns that were common to all the participants as well as those that appeared to be different (Strauss, 1987: 81).

Ordinarily the use of computer assisted qualitative data analysis software (CAQDAS) for analyzing my data would have been convenient, but no Arabic versions of relevant programmes were available at the time.

**Coding process**

By constantly comparing codes with each other, I am able to refine the conceptual codes and analyse the social situation. This approach has proven to be effective in much of the sociological literature dealing with health and illness and is a major feature of grounded theory. This coding process includes the procedures that researchers use to interpret and organize data, which are referred to as 'conceptualizing' and 'reducing' data, 'elaborating' categories, and 'relating' through a series of statements (Strauss and Corbin, 1998; Dey, 1993, 1999). The coding process consists of five stages. My analysis was carried out by using the so-called 'pen and paper' method.

**Stage 1**

During this stage, I made distinctions amongst the women based on the duration of their disease and transplant status. I also divided them based on their age and marital status. I further sub-divided married women into groups that included having children or not. These subgroups were further divided by the age of their children. I then organized the transcripts accordingly.

**Stage 2**

I scrutinized each transcript line-by-line and paragraph-by-paragraph to ascertain differences in issues being investigated and these similarities and differences were highlighted in the margins. A flow chart indicating interrelated concepts and dimensions was drafted to set an analytical approach for the data analysis chapters.

It is important to emphasize that the categories were identified in the transcripts themselves and not from any particular theory. This process is a dynamic one since themes changed and new ones arose out of the context of the participants' personal experiences and not from my preconceived ideas. After categorizing the various issues, I labelled them for identification using different colours. This procedure also made retrieval of information more convenient and efficient.

**Stage 3**

The data was further examined to identify additional themes and concepts that arose out of these categories. A lighter shade of the same colour as that used for a
specific category was used for highlighting the themes and concepts that belonged to that category. I found that some of the same themes belonged to more than one category. At the end of this stage, the themes were again scrutinized. Organizing data in this manner uncovered the hidden meanings embedded within these themes that were found primarily in the participants' narratives.

**Stage 4**

In this stage, I carefully examined each theme to find the similarities and differences that carried over to the different categories within the transcripts. I then compared the same theme from one category to another. I also looked to see how often a particular theme was repeated. There were times when I discovered a response that was not raised in other transcripts due to a participant's special circumstances (education, employment). Later, these new themes had to be coded.

**Stage 5**

After reviewing all the data that emerged from the narratives, I used a holistic approach when integrating all my findings. According to Strauss and Corbin (1998), 'conceptualizing' data is a vital procedure that is a part of the coding process that researchers use to interpret and organize data. I identified concepts that were generated from participants' narratives. Distinctions and similarities in concepts were drawn and then charted into categories that were examined and analysed. In my study, the following categories emerge as key concepts: resources and sources of support, family care-giving roles and relationships, perceptions of self and identity, making sense of their illness, and managing their everyday life.

Relevant quotations that are extracted directly from the transcripts are used to illustrate these women's experiences and their ability to manage their illness and disability as they relate to each theme or sub theme. I adopted the conventional symbols used in transcribing: italicized single quotes for Arabic terms and names. Square brackets [ ] are used to indicate translated terms or other insertions. Three dots … are used to indicate interruptions, and to denote editorial omissions at the beginning or end of a transcript; and parenthesis ( ) are used to add any information from the non-recorded discussions, observation or field notes. The coding symbols used include: pseudonym, age group (A: 24-28 years, B: 29-35, C: 36-39, D: 40-59) and marital status (S: Single, M: Married, MS: Married but Separated, D: Divorced, W: Widowed); for example: Sabra pseudonym (C-M) (refers to age between 36-39 years and married).

The following five interrelated data analysis chapters critically analyse the impact of end-stage renal failure and haemodialysis therapy on Saudi women. Each chapter addresses different recurrent themes and sub-themes that are identified in the narratives of the participants. How these women attempted to manage their illness and disability in order to maintain their way of life are crucial issues.
Profile of Saudi women interviewed

Qualitative data was collected from two in-depth interviews with 50 Saudi women suffering from ESRF. The interviews were designed in a semi-structured question format to obtain data pertinent to the aim of this research (Appendix E). The data generated from these interviews covered a wide-range of issues directly related to socio-religious values as well as economic circumstances of these Saudi women. The socio-demographic characteristics of the participants are shown in Table 6.1 and a brief profile of each participant is provided in Appendix F.

Table 6.1 summarises the socio-demographic characteristics of the Saudi women interviewed. The variables were analysed according to four age groups of participants (age groups A-D). The participants ranged in age between 24 to 59 years; with (54%) falling within the 40-59 years (age group D). The table shows that most of these women are married (42%), (18%) are widowed, (16%) remained single, (14%) are legally married but separated, and that the smallest number (10%) of women are divorced. All of the single women fell into the youngest age groups (A and B); whereas, all the widows were the oldest women (in age group D). None of the (10%) who are divorced belong to the younger age groups (A and B).

It is important to note that the eight women in age groups A and B who do not have any children are single. Since Saudi socio-religious norms assume that single women are childless, there are only 42 women who are included in the 'number of children' category. The only woman without any children that is included in this data is divorced and is in age group D. The largest group of ever-married women (18 women or 43%) have 7 or more children, (31%) have 4-6 children and (24%) have 1-3 children.

Kin-related marriage to cousins and polygamy are permitted by Islamic law and practiced in Saudi society. Cousin-marriage is a common practice, with (71%) of participants married or previously married to cousins. This data reflects the norm of general Saudi society where statistics from the Ministry of Economy and Planning 2005-09 indicate that kin-related marriage among women continues to be high although the preference for this type of marriage among younger women is decreasing (p. 307). In relation to polygamy, (36%) of participants are or were involved in a polygamous relationship. This proportion would have been higher in the past and is indicative of changed patterns of marriage in Saudi society where polygamy is on a relative decline amongst younger women. It is also important to note that the largest number of participants who are in a kin-related and/or polygamous marriage are within the older two age groups (C and D – over 35).

The majority (62%) of the Saudi women with ESRF are illiterate, of whom the largest number (21 out of 31) are in the oldest age group D (over age 40). The (12%) who stated that they could read and write, never went to school and instead learned to read at religious centres for the purpose of studying the Quran. Even though (20%) of the participants stated they had some level of formal education (elementary, intermediate, secondary), it was later revealed that they had not completed the required courses needed to obtain a certificate of completion. The teacher’s institute that three participants attended after finishing elementary school was only for two years. The level of learning at the institute was equivalent to high school and cannot be compared to the present day educational system, where
students studying to be a teacher must graduate from a university with a four year degree. The sample of women in the study primarily belongs to the low socio-economic group of Saudi society. This finding is based on both the quantitative and qualitative study that reveals that (95%) of these women have never been employed and therefore did not have any personal income of their own. On the basis of this, they had to depend on their male legal guardian who did not have adequate income to spare for economic support: household income for (14%) of the respondents was between 4000-4999SR; (26%) was between 500-3999SR (£68-542); and only (13%) was 5000SR (£678) or more (see Table 5.1). It is important to note that this information is based solely on the survey questionnaire (Appendix D) since there is no other available source of information regarding these women's personal and household income.

An overwhelming (92%) of these women had never been employed and the remaining (8%) had been forced to leave their employment due to ESRF. This is the reason why 45 women (90%) did not have any personal income and had to rely entirely upon household income which is provided by the participant's legal guardian (father 16%; husband 42%; brother 20%; uncle 12%; and son 10%).

To understand participants' household composition, the key variables are associated with marital status (Table 6.2; Figure 4.1). The reason being is that according to Saudi socio-religious norms, mahram [males related to the female by a certain degree of sanguinity] or legal guardians of women depend on whether women are single, married or previously married. In Table 6.2, previously married includes separated, divorced and widowed women. Although separated women are legally considered married (yet they are no longer living with their husband) under Saudi law, they are included in the previously married category for the purpose of determining household composition. The data reveals that none of the participants live alone which highlights Saudi cultural norms that Saudi women rarely live by themselves, regardless of age or marital status.

An important observation made from the data that is peculiar to Saudi society is the distinction made among nuclear, extended and in-laws (Figure 4.1) based on marital status and kin relationships. Unlike western society, once a married Saudi woman's marital status changes to separated, divorced or widowed (previously married); her parents and siblings (and their wives and children) are no longer considered extended family, but are included in al-usra her [immediate family]. However, her married uncle and his family remains her extended family which all participants refer to as al-akarib [extended], when speaking about them. Again, this has to do with Saudi cultural norms that dictate that women must live with a male guardian; once they move out of their husband's home, they must move into the home of their father and/or brother; or uncle. Table 6.2 reflects this tradition which reveals that all eight single women lived with their parents; six previously married women moved back with their parents; and the remaining 15 previously married women either moved in with their son, brother, or uncle who became their legal guardian because their father was deceased.
Table 6.1
Demographic characteristics of Saudi women interviewed according to age group (n=50)

<table>
<thead>
<tr>
<th></th>
<th>(A) 24-28</th>
<th>(B) 29-35</th>
<th>(C) 36-39</th>
<th>(D) 40-59</th>
<th>n=50</th>
<th>Col % =100%</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Marital status</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>S: Single</td>
<td>3</td>
<td>5</td>
<td>0</td>
<td>0</td>
<td>8</td>
<td>16</td>
</tr>
<tr>
<td>M: Married</td>
<td>1</td>
<td>4</td>
<td>5</td>
<td>11</td>
<td>21</td>
<td>42</td>
</tr>
<tr>
<td>MS: Separated</td>
<td>2</td>
<td>0</td>
<td>0</td>
<td>5</td>
<td>7</td>
<td>14</td>
</tr>
<tr>
<td>D: Divorced</td>
<td>0</td>
<td>0</td>
<td>3</td>
<td>2</td>
<td>5</td>
<td>10</td>
</tr>
<tr>
<td>W: Widowed</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>9</td>
<td>9</td>
<td>18</td>
</tr>
<tr>
<td><strong>Number of children</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>None</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>1-3</td>
<td>2</td>
<td>2</td>
<td>1</td>
<td>5</td>
<td>10</td>
<td>24</td>
</tr>
<tr>
<td>4-6</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>12</td>
<td>13</td>
<td>31</td>
</tr>
<tr>
<td>7 or more</td>
<td>0</td>
<td>2</td>
<td>7</td>
<td>9</td>
<td>18</td>
<td>43</td>
</tr>
<tr>
<td><strong>Kin-related marriage</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>0</td>
<td>3</td>
<td>5</td>
<td>22</td>
<td>30</td>
<td>71</td>
</tr>
<tr>
<td>No</td>
<td>3</td>
<td>1</td>
<td>3</td>
<td>5</td>
<td>12</td>
<td>29</td>
</tr>
<tr>
<td><strong>Polygamous marriage</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>1</td>
<td>0</td>
<td>5</td>
<td>9</td>
<td>15</td>
<td>36</td>
</tr>
<tr>
<td>No</td>
<td>2</td>
<td>4</td>
<td>3</td>
<td>18</td>
<td>27</td>
<td>64</td>
</tr>
<tr>
<td><strong>Educational level</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Illiterate</td>
<td>1</td>
<td>3</td>
<td>6</td>
<td>21</td>
<td>31</td>
<td>62</td>
</tr>
<tr>
<td>Can read and write</td>
<td>0</td>
<td>3</td>
<td>2</td>
<td>1</td>
<td>6</td>
<td>12</td>
</tr>
<tr>
<td>5-6th grade</td>
<td>2</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>3</td>
<td>6</td>
</tr>
<tr>
<td>7-8th grade</td>
<td>1</td>
<td>2</td>
<td>0</td>
<td>1</td>
<td>4</td>
<td>8</td>
</tr>
<tr>
<td>10th grade</td>
<td>2</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>3</td>
<td>6</td>
</tr>
<tr>
<td>Teacher's institute</td>
<td>0</td>
<td>1</td>
<td>0</td>
<td>2</td>
<td>3</td>
<td>6</td>
</tr>
<tr>
<td><strong>Employment status</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Never employed</td>
<td>5</td>
<td>8</td>
<td>8</td>
<td>25</td>
<td>46</td>
<td>92</td>
</tr>
<tr>
<td>No longer working</td>
<td>1</td>
<td>1</td>
<td>0</td>
<td>2</td>
<td>4</td>
<td>8</td>
</tr>
<tr>
<td><strong>Type of income</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Any Personal income</td>
<td>1</td>
<td>1</td>
<td>0</td>
<td>3</td>
<td>5</td>
<td>10</td>
</tr>
<tr>
<td>Household income</td>
<td>5</td>
<td>8</td>
<td>8</td>
<td>24</td>
<td>45</td>
<td>90</td>
</tr>
<tr>
<td><strong>Main Source of income</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Father</td>
<td>3</td>
<td>4</td>
<td>1</td>
<td>0</td>
<td>8</td>
<td>16</td>
</tr>
<tr>
<td>Husband</td>
<td>1</td>
<td>4</td>
<td>5</td>
<td>11</td>
<td>21</td>
<td>42</td>
</tr>
<tr>
<td>Brother</td>
<td>2</td>
<td>1</td>
<td>1</td>
<td>6</td>
<td>10</td>
<td>20</td>
</tr>
<tr>
<td>Uncle</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>4</td>
<td>4</td>
<td>8</td>
</tr>
<tr>
<td>Son</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>6</td>
<td>7</td>
<td>14</td>
</tr>
<tr>
<td><strong>Legal guardian</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Father</td>
<td>1</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Husband</td>
<td>2</td>
<td>4</td>
<td>1</td>
<td>0</td>
<td>8</td>
<td>16</td>
</tr>
<tr>
<td>Brother</td>
<td>0</td>
<td>4</td>
<td>5</td>
<td>11</td>
<td>21</td>
<td>42</td>
</tr>
<tr>
<td>Uncle</td>
<td>0</td>
<td>1</td>
<td>1</td>
<td>6</td>
<td>10</td>
<td>20</td>
</tr>
<tr>
<td>Son</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>6</td>
<td>6</td>
<td>12</td>
</tr>
</tbody>
</table>

* Single women are not included, n=42
### Table 6.2

**Household composition of interviewed participants according to marital status**

<table>
<thead>
<tr>
<th>Household composition*</th>
<th>Single</th>
<th>Married</th>
<th>Previously married</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>MS</td>
<td>D</td>
<td>W</td>
</tr>
<tr>
<td>With parents, siblings or unmarried</td>
<td>3</td>
<td>0</td>
<td>4</td>
</tr>
<tr>
<td>brother and siblings</td>
<td></td>
<td></td>
<td>1</td>
</tr>
<tr>
<td>(immediate/nuclear family)</td>
<td></td>
<td></td>
<td>1</td>
</tr>
<tr>
<td>Parents, siblings and one or more</td>
<td>4</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>extended family member</td>
<td></td>
<td></td>
<td>0</td>
</tr>
<tr>
<td>Parents and one or more extended</td>
<td>1</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>family member</td>
<td></td>
<td></td>
<td>0</td>
</tr>
<tr>
<td>Husband and offspring</td>
<td>0</td>
<td>14</td>
<td>0</td>
</tr>
<tr>
<td>Husband, offspring and one or more</td>
<td>0</td>
<td>3</td>
<td>0</td>
</tr>
<tr>
<td>extended family member</td>
<td></td>
<td></td>
<td>0</td>
</tr>
<tr>
<td>Husband, offspring and in- law</td>
<td>0</td>
<td>4</td>
<td>0</td>
</tr>
<tr>
<td>Offspring</td>
<td>0</td>
<td>0</td>
<td>2</td>
</tr>
<tr>
<td>Married son, his family and</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>offspring</td>
<td></td>
<td></td>
<td>0</td>
</tr>
<tr>
<td>Married brother, his family and</td>
<td>0</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>offspring</td>
<td></td>
<td></td>
<td>1</td>
</tr>
<tr>
<td>Married uncle, his family, and</td>
<td>0</td>
<td>0</td>
<td>2</td>
</tr>
<tr>
<td>offspring (extended family)</td>
<td></td>
<td></td>
<td>2</td>
</tr>
<tr>
<td><strong>n=50</strong></td>
<td>8</td>
<td>21</td>
<td>7</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>5</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>9</td>
</tr>
</tbody>
</table>

*For details on participant's household composition and key family relationships see Appendix F and Figure 4.1

It is interesting to note that although the traditional Saudi family has included both the nuclear and extended family within one household, Table 6.2 shows that only 12 out of 50 of the participants live with both their immediate/nuclear and extended families. The data indicates that the largest number of participants regardless of marital status, lives only with their nuclear family (34 out of 50) which is indicative of modern day Saudi society moving away from the traditional Saudi household towards a nuclear one (MOEP, 2005-9: 315).

In conclusion, the data generated from the qualitative interviews with Saudi women with ESRF as revealed in Tables 6.1 and 6.2 shows that socio-demographic characteristics are closely associated with age and marital status.
PART III
DATA ANALYSIS
Chapter Seven
The Process of Making Sense of ESRF for Saudi Women

This chapter examines how Saudi women with end-stage renal failure (ESRF) attempt to make sense of their illness. All 50 participants had gone through a process of making sense of their illness and throughout that process their perceptions of their illness had changed as well as their identity and self-concept. At the onset of ESRF, these women failed to recognize their illness, which impeded them from making sense of the illness. Initially, it was their lack of awareness and understanding of ESRF and their religious and cultural beliefs that made them perceive ESRF as a common sickness that would soon pass. Lack of understanding of the disease kept them from connecting their symptoms to a chronic illness and during this time period they resorted to common remedies influenced by the cultural norms of society.

Impediments to making sense of illness

It is important to note that in order for chronically ill women to adjust to their new way of life they had to make sense of their illness. But it soon became apparent as they discuss their experiences of living with ESRF, that at the onset of ESRF certain socio-religious factors in their lives impeded them from making sense of their illness. These impediments are: lack of awareness and understanding of their illness, and religious and cultural beliefs.

Lack of awareness and understanding

The women in my study lacked the awareness to identify their difficulties prior to being diagnosed. All participants reported that they had difficulty understanding the true nature of their symptoms because they attributed them to normal female symptoms. This lack of understanding can be attributed partially to the high percentage (almost 80%) of illiteracy amongst the participants. Not being able to access and understand information about illness and disease greatly contributed to their lack of general awareness of renal disease itself. This in turn prevented them from recognizing their symptoms as being associated with a serious illness, which they originally considered to be temporary discomforts that they or other female relatives had experienced before. Since none of these women dwelled on their symptoms, they were unaware that their discomfort was symptomatic of renal failure and continued to struggle with their daily tasks and activities.

More importantly, this lack of awareness and understanding prevented them from immediately seeking medical assistance, which prolonged the time between the onset of their symptoms and their treatment. It was only when they faced intolerable discomfort, i.e., sudden attacks of acute back pain, fainting spells, nausea, vomiting and chills, did they decide to see a physician. The following comments are revealing in the way they illustrate how participants' interpreted their symptoms:

'I used to drink some mint when I felt like it was indigestion or a sense of body fullness... like I ate too much or something.' Sabra (C-M)
'I never told my husband or my family about any of the back pain I was having. I used to just take some rest and then return back to whatever chore I was doing.' Basma (B-M)

'Only when my pain became severe and I started to vomit did my husband (now ex-husband) take me to see a doctor.' Hayat (C-D)

These comments reveal that all women in this study initially perceived their discomfort as being 'normal' and did not even think to relay their discomfort to their spouse or other members of their family to avoid unnecessary worry about a problem they did not even consider serious. By the time these women were finally diagnosed, they had already reached the end-stage of their renal disease

Religious and cultural beliefs

Saudi religious and cultural beliefs were found to be another impediment to participants' ability to make sense of their illness. Religious norms influence the expectations and standards that Saudi society places on its members; regardless of their social, economic, or physical status. How a Saudi woman perceives her illness and her relationship to it is usually dictated by her religious belief that everything that happens to her is a part of Allah's will. She is supposed to understand that all aspects of her life, whether positive or negative, happy or tragic, are earthly tests; and how she responds to them reflects her faith and eventually, her place in the Hereafter. This perception is not just a personal one; in fact, it is embedded throughout Saudi society. It is very interesting to note that at the time of diagnosis and even before receiving medical advice, their doctors reminded them that as Muslims they must have patience and faith. This 'spiritual' reminder is welcomed amongst all Saudis who are facing any difficulties. It is this foundation that supports them while confronting numerous challenges and attempting to make sense of their illness:

'Even before telling me what was wrong with me or anything about my illness the doctor reminded me that it was Allah's [God] will and that I should have a strong faith and except my illness willingly.' Hasna (C-M)

In addition, there are certain beliefs held amongst Saudi people that once were considered to have a religious basis but are today thought to be merely cultural superstitions. One such belief which was prevalent in the narratives, is the shared belief in the ayn [evil eye], where an envious person might comment or compliment someone without saying Mash'Allah, [God protect you from envy].

Some participants base their belief on specific incidents or people who commented or complimented them without saying Mash'Allah:

'Wallah [I swear to God], it was a strong ayn [evil eye] that hit my health. I felt it one day when I had a large gathering in my house and one of the ladies without saying Mash'Allah [God protect you from envy], she said I don't believe you did all this cooking with out any help.' Hiba (D-M)

Others loosely blame the 'evil eye' for their illness without having any concrete basis:
"Deep in my heart I feel that it is somebody's ayn [evil eye] that caused the illness." Rehab (D-D)

This concept of people casting an evil eye on a person and causing actual harm is founded on recorded incidents in Islamic history. Since there is a religious acknowledgement of this concept, some people use this as an explanation for occurrences that they do not fully comprehend. Even though participants have received their diagnosis from a medical specialist, the oldest participants in their fifties in particular still harbour the belief that their illness is the result of someone casting an 'evil eye' on them.

The belief in this concept is a genuine one and these women are sincere in citing the 'evil eye' as a real cause for their illness. Yet, these women may be subconsciously using this cultural belief to aid them in making sense of their illness without questioning God's will. They may understand the biological reasons for their dysfunction, but they are trying to come to terms with the reason why they were the ones inflicted with a chronic disease.

The perceptions of Saudi women with ESRF did not change until after they were able to recognize their illness. Once they recognized the chronic nature of ESRF, they had to face the reality of the illness and confront all the changes it entails. By confronting these changes, most eventually learnt to adapt to their illness. The oscillating nature of this entire process of making sense of ESRF is revealed as these women move back and forth while living with ESRF. It is continuous as the illness is ongoing, for all these women are constantly confronted with challenges that require them to adjust and manage accordingly. If we were to try to map this out on a graph, we would detect the occurrence of peaks and valleys throughout this process.

The following part of this chapter discusses the physical, emotional and psychological changes Saudi women suffering from ESRF encounter in trying to live with this chronic illness. The process that these women undergo during the course of living with ESRF includes recognizing the illness, living with the illness, and adapting to it.

Recognizing the illness

Recognizing the illness is part of the process that enables these women to make sense of their illness. As stated above, participants' lack of awareness and understanding of their illness inhibited them from recognizing their condition at the initial stages of ESRF.

It was only after the participants visited a doctor for medical care, that they were made to recognize that they had an illness. Once the doctor informed them that they had a serious health condition, they began to recognize that there was an actual illness that was causing all the symptoms they had previously experienced. Thus, their haemodialysis (HD) therapy can be seen as the determining factor for recognizing the illness. The participants can be divided into two categories, first, those women who visited the doctor earlier were diagnosed with chronic renal
disease and treated with medication; and second, those who had not sought medical care until much later and were diagnosed with ESRF and immediately placed on haemodialysis.

A significant difference in perception of the illness existed between the 25 participants (3 single; 15 married; 3 divorced; 4 widowed) who suffered severe symptoms prompting them to visit the doctor earlier than their 25 counterparts (5 single; 13 married; 2 divorced; 5 widowed) who did not seek medical attention until much later. Since the former group was informed about the nature of their illness and were placed on medication before reaching the end-stage of their renal disease, they had time to recognize the seriousness of their condition while also maintaining a sense of hope for recovery. Their hope was based on the fact that approximately 6 to 9 months lapsed between the time of their diagnosis and the onset of their HD therapy. This time period allowed them to believe that their condition may improve and that HD therapy would be unnecessary:

"All the time I was taking my medication, I thought that it was going to get my kidney better. I never realized that even with the medication my condition was still getting worse." Rawan (D-MS)

On the other hand, the other 25 women were immediately confronted with the permanency of ESRF as soon as they were placed on haemodialysis. Since these women waited so long before they visited a physician due to their lack of awareness that an illness actually existed, they were already at a serious stage of ESRF when presented with the diagnosis. They neither had the time to adjust to the idea of being ill for the rest of their life, nor had the hope for recovery as their counterparts had:

"The doctor immediately told my husband that my kidneys were not working and that I needed to have the wash (dialysis). I had no time or opportunity to even think what this wash (dialysis) meant." Luýfiah (D-M)

Even after their diagnosis, all participants regardless of age and marital status still did not recognize that the occurrence of symptoms associated with ESRF was actually related to the illness. This non-recognition may have stemmed from the nature of ESRF itself, since the majority of its symptoms can be easily mistaken for other illnesses that are more commonly known. One of the most easily mistaken symptoms is pain in the lower back that could be mistakenly attributed to premenstrual symptoms, as opposed to ESRF:

"It was hard for me to believe what the doctor told my husband (now ex-husband) about my kidneys not working; I kept telling him the doctor was wrong and my back pain was due to my late period; just as it was the month before." Tagreed (D-W)

Since it is normal behaviour for an individual to make sense of their illness by first comparing it to something that is familiar and therefore less threatening, these women even blamed their symptoms on events that occurred at home, e.g., a sudden rise in blood pressure was due to a family argument or a severe headache was brought on by the children's loud activities:
'It never came to my mind that it was anything serious; I thought my headaches were due to the loud noises made by my children.' Abeer (B-M)

Immediately after dialysis, all participants (regardless of age and marital status) still neglected their health management, because they perceived themselves as being 'well'. They had exaggerated their sense of physical health (e.g., improved breathing, decreased bloatedness) when they compared it to how they felt prior to receiving dialysis. It was as if they had forgotten they had been diagnosed with ESRF, so they failed to make a connection between their symptoms and the illness:

'Af ter having my wash (dialysis), I felt much better, so I thought this was it; that I could go back home and do my normal housework (cleaning, ironing) once again.' Fatin (A-M)

Their inability to recognize the illness and its symptoms was partially due to their initial state of denial. All participants reported that the news of having a chronic disease was both shocking and terrifying to them. Their instinctive response was to protect themselves from extreme emotional distress that resulted from hearing such devastating news and their denial seemed to allow them to adjust to the enormity of the circumstances:

'I was never able to believe what the doctor told him (her husband) about my kidneys not working. I kept thinking that it will soon go away. I never imagined that it was so serious.' Mai (D-M)

Since all participants in this study were in a state of denial following their diagnosis, their doctors had to continuously remind them to constantly manage their initial symptoms through strict fluid intake, hygiene and medication. But once they were in the familiarity of their homes they again minimized their symptoms and forgot their doctor's orders. It was only later, when they were placed on a fixed schedule of haemodialysis and repeatedly returned to the kidney centre for haemodialysis, that they recognized the reality and seriousness of the illness:

'The doctor at the dialysis centre always reminded me that even though the wash (dialysis) will relieve me from many of the discomforts I'm feeling, I will still have to take my medication regularly and monitor my fluid intake very closely.' Sumaya (D-M)

It can be seen from the above excerpts that for different reasons the participants were either unable or unwilling to recognize their symptoms as being associated with ESRF. At home, amongst familiar surroundings, women derived some feelings of comfort which enabled them to ignore their symptoms; yet when visiting the dialysis centre they were reminded of the chronic nature of their illness and therapy.

**Alternating between fear and comfort**

As mentioned above, all of these women did not perceive the seriousness of their illness until after they were involved in the routine of their haemodialysis
treatment. It seems that depending upon their physical location their feelings fluctuated from fear to comfort. They identified their fear with the place of treatment, the dialysis centre; and their comfort zone was associated with their homes. While they were at the dialysis centre undergoing treatment, they related how they experienced extreme anxiety and uncertainty about the entire treatment procedure. The visualization of being hooked up to a machine where they could actually see their blood being drained into a tube, and then filtered and returned to their bodies through another tube brought on fear that may have contributed to their feelings of nausea, faintness, headaches and mental distress. In fact, in the early phase of their dialysis sessions, the machines themselves appeared threatening and ominous. The women even named the machine to reflect their fear and distrust: 'the torture device'. They not only referred to it by this name amongst themselves, they used this epithet when talking to the nurses about their treatments. Interestingly, as the participants became accustomed to the machines, the epithet no longer represented its evil connotation:

'When I first started my wash (dialysis), the worst thing I experienced was being hooked up to that 'torture device' (dialysis machine). Only several months after my wash (dialysis) was I able to get myself accustomed to this 'machine'.' Ruba (B-S)

The dialysis centre also triggered fearful reactions for participants because of the tragic incidents that they either saw or heard about occurring there. During their dialysis session, some saw women faint, bleed profusely and unfortunately die from a heart attack while receiving treatment. Stories about these unfortunate events quickly passed from medical personnel to patients, so even those who did not actually witness them were adversely affected:

'You know when I first started coming to the dialysis centre for my wash (dialysis) the only worry my friends (fellow-patients) and I had was of having a heart attack, bleeding or possibly even dying while we are receiving our wash (dialysis). The stories I heard from other fellow-patients and the nurses makes me feel uncomfortable every time I'm having my wash (dialysis).' Mana (B-M)

When these women arrived home, they immediately found themselves relaxing and returning to what they considered a state of normality. Their sense of relief was easily transferred to feelings of physical comfort. In other words, they were lulled into a false sense of well-being which led them to subconsciously ignore or forget their doctors' orders. Their happiness to see their family and to be surrounded by familiar objects seemed to insulate them from the seriousness of their illness:

'Alhamdulillah [thank God] all the anxiety and worries about bleeding or something else happening at the dialysis centre when I'm having my wash (dialysis) fades away when I return home and have my children around me.' Buthainah (C-D)

These oscillating experiences of fear and comfort fluctuate back and forth while women attempt to face the reality of the illness.
Living with the reality of the illness: identity and self-concept

Living with the reality of the illness is another aspect of the process that all participants go through while making sense of their illness. This reality is not only based on the physical changes of ESRF, but the psychosocial changes that define chronically ill women in Saudi society. The psychosocial changes associated with the illness that affect how a woman perceives herself are: identity and self-concept. Identity is associated with the culture of a society that defines a woman's roles and relationships with other members of that society. Self-concept is the psychological perception she has of herself which is influenced by her culture. Both social and psychological perspectives are taken into consideration when analyzing how chronic illness affects Saudi women's perceptions of themselves. In addition, these perceptions are shaped by marital status and age.

Saudi society has set rigid standards defining roles and relationships by which all women are compared. These standards are passed down from generation to generation and are rarely questioned or disputed. Unfortunately, chronically ill Saudi women are unable to meet the societal criteria that define the identity of a successful woman as being married and raising their children. Thus, they automatically perceive themselves as failures because they adopt a self-concept that limits their self-worth to societal expectations of women, i.e., maintaining a healthy and attractive appearance, having satisfactory marital relations and the ability to bear and rear children:

‘If I don't get married and have children like my sisters, I will not be able to have any say in any matter that concerns me or my life. My mother and aunt are examples of this, except my mother still has some say over me and my brother. But my divorced aunt, who has no children, is treated like an older child.’ Nawara (B-S)

Dallal reveals how a subtle difference in the way she was treated due to her inability to have children as a condition of ESRF made her feel inferior to other women who had children:

‘My husband's (now her ex-husband) request from a government agency to get approval for a driver was denied because we had no children. Needing a driver for taking children to school is the most acceptable reason for hiring a driver. It did not matter that I am sick; I wasn't a mother so they felt I didn't need a driver. Since I am not a mother, I have no value or worth.’ Dallal (D-D)

In order to recognise the reality of the illness, all participants had to confront the various physical, emotional and psychological changes that accompany their condition. During this period, their 'changes in physical appearance', 'changes in physical ability' and 'changes in cognitive ability' are identified as crucial to their self-identity and feelings of self-worth.

Changes in physical appearance

Initially, physical changes, such as, discoloration of their teeth and skin, bruised arms and weight loss, may not be noticeable to family members and
acquaintances, but they seem magnified in the eyes of the patients and can cause low self-esteem and isolation. These women experience low self-esteem because they feel they have fallen short of their cultural standards of beauty. This in turn affects how they act and react towards others. Unintentionally, they may alienate themselves from family members and acquaintances out of embarrassment and shame. Their negative self-concept elicits negative reactions which may further lead to mental conditions that eventually impedes them from getting accustomed to their changed appearance:

'It is hard to look well when I don't feel well. All the changes taking place in my body makes it difficult for me to put on make-up and fix my hair. No matter what I do to look decent, I still feel ugly because I'm always tired. My family doesn’t see that I'm trying my best; they think I can do better if I try harder. So what's the use in making all this fuss when no one recognizes my efforts? I only feel worse when they continue to push me to make myself look better for my husband and relatives.' Rabha (C-M)

Diagnosis is difficult to make at the early stages of chronic renal disease because the kidneys are still partially functioning. Therefore, these participants did not witness any drastic changes in their physical appearance prior to treatment. Physical appearance is not discussed by any of the participants in their narratives dealing with recognizing the illness. Thus, it may be implied that it was not yet an issue. But once these women were undergoing treatment, they were confronted with a barrage of physical manifestations of their illness. It was during this time when these women began to experience personal fears about the drastic changes that they saw in their physical appearance. Their medical regimen (including haemodialysis) which was the first major burden they had to adjust to was no longer their only concern. They now worried about their appearance every time they looked into the mirror. They were beginning to detect the discoloration of their teeth and skin every time they tended to their personal hygiene; the bruised arms resulting from the repeated access to the vein used for dialysis; and weight loss as a side-effect of the illness, etc. These changes in physical appearance affected the participants differently depending upon their marital status. It is within marital status categories that age has a major influence on these women's self-perception.

Single women

All eight single women (24-35 years) (Table 7.1) were noticeably more preoccupied with changes in their physical appearance because they still had dreams of marrying and having a family. They were concerned that their chances of marriage would be greatly jeopardized by what they believed was an unattractive appearance. One young woman expressed how her changed physical appearance affected her state of mind:

'It seems that I think about all things I may never have in my life. It makes me very sad to think I may never experience the excitement my married sisters and cousins have had planning their weddings. I get depressed because I don't know what kind of life I will have and there are times when I avoid talking with them about this subject. It makes me too sad.' Bayan (A-S)
Even though they knew that marriage proposals would be rare once their illness was known to family members and acquaintances, the possibility of a successful transplant coupled with their age kept their dreams alive. But at times, their focus on the changes in their physical appearance caused them to suffer from emotional and psychological problems which led to depression and a deep sense of regret for what they may never have.

Table 7.1
Age group and marital status of sample members (n=50)

<table>
<thead>
<tr>
<th>Age groups</th>
<th>Single (S)</th>
<th>Married (M)</th>
<th>Separated (MS)*</th>
<th>Divorced (D)</th>
<th>Widowed (W)</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>(a) 24-28 yrs.</td>
<td>3</td>
<td>1</td>
<td>2</td>
<td>0</td>
<td>0</td>
<td>6</td>
</tr>
<tr>
<td>(b) 29-35 yrs.</td>
<td>5</td>
<td>4</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>9</td>
</tr>
<tr>
<td>(c) 36-39 yrs.</td>
<td>0</td>
<td>5</td>
<td>0</td>
<td>3</td>
<td>0</td>
<td>8</td>
</tr>
<tr>
<td>(d) 40-59 yrs.</td>
<td>0</td>
<td>11</td>
<td>5</td>
<td>2</td>
<td>9</td>
<td>27</td>
</tr>
<tr>
<td>Total n=</td>
<td>8</td>
<td>21</td>
<td>7</td>
<td>5</td>
<td>9</td>
<td>50</td>
</tr>
</tbody>
</table>

*Separated women (MS) are still considered legally married but are separately classified in this table for purposes of clarification.

Married and separated women

The 28 married and separated women in this study were also divided by age groups: 3 women are in age group (a) 24-28 years, 4 women are in age group (b) 29-35 years, 5 women are in age group (c) 36-39 years and 16 women are in age group (d) 40-59 years (Table 7.1). The problem concerning changes in physical appearance and its impact on self-perception was found to be more prominent amongst the younger married women in age groups (a thru c) than their older counterparts in age group (d). The younger married women felt more threatened by the manifestations of their illness because of their preoccupation with thoughts of their physical appearance or body-image. They often compared themselves to the images they saw on television and in magazines:

'I see how beautiful the film-stars are in the magazines and realize now that I am sick, I can never maintain my looks or keep up with the styles. I can hardly get to the dialysis centre for treatment, how can I take the time to shop for cosmetics and practice applying it as I used to?’ Afrah (B-M)

Since it is possible in Saudi society for a man to take more than one wife, all married participants regardless of age, felt the pressure of maintaining their physical appearance. They expressed fear that their husbands might either divorce them or marry second wives. In fact, 15 of the 42 women who were ever married
reported their husbands marrying second wives after the onset of their illness. Seven of the 28 married women admitted to being separated from their husbands after the onset of the illness and all 5 of the divorced participants blamed their marital status on the illness since they were divorced after the onset of the illness:

'I know I need to keep up my appearance for him (her husband); I don't want him to take a second wife like other men do. But I get depressed because I know I don't look good anymore and I always worry that one day he will want someone else.' Badia (C-M)

Even the most mundane comments directed at these women's physical appearance were perceived as personal criticism which either caused them to attempt to conceal their changed appearance or pull away from their social circle. Either response made them feel isolated:

'I don't want my relatives and al-jeran [neighbours] to see how bad I look, so I always try to hide the bruises on my arms by wearing long sleeves. I even try to look healthy by wearing powdered blush on my face.' Abla (D-M)

'Many times my relatives or al-jeran [neighbours] comment that I look tired and pale. I know they don't mean to hurt my feelings, so I try to ignore it. But I wish they would keep this to themselves. Sometimes I just find a place to be alone, so that I don't have to face them.' Waseela (C-M)

All married and separated women reported that the constant struggle to meet the expectations of their family members and society was tiresome and when they failed, their feelings of shame and guilt were turned inwards. Since these women believe that they can no longer live up to social expectations, they suffer from negative self-concept and low self-esteem.

Divorced and widowed women

None of the divorced or widowed women fall within the younger age groups (a) and (b) (Table 7.1). Similar to the older married women (40-59 years) in age group (d), the primary focus of the divorced and widowed women is on their ability to perform their roles and maintain their relationships with family members; rather than worrying about their body-image:

'At my age and situation I no longer think about how I look. The only important thing is for me to be able to take care of my home and children. I don't have the energy to worry about anything else.' Sultana (D-W)

The main difference between these women and their married counterparts is that they no longer have a husband, thus the marital relationship is no longer a concern. However, 11 out of the total 14 divorced and widowed women had been forced to move in with their legal guardians. This phenomenon raises various social issues, such as resulting in women's lack of social participation and loss of domestic authority, that affect women's self-concept (discussed in Chapter 10).
Summary

All single or married women expressed alarm by the minor changes in their physical appearance even when they were not yet detected by family members and friends. As the illness progressed and bodily changes became more prominent and visible to others, they tried to conceal these physical changes. They wanted to avoid comments made or questions posed by family members and acquaintances. Their intentions were to divert the attention of others away from these physical changes. They resorted to wearing long sleeves to cover their bruised arms, applying make-up in attempts to conceal their paleness and discoloration, and holding up their hands to their mouths to hide their discoloured teeth while talking and smiling. In contrast, the concerns of the divorced and widowed women were focused on their roles and relationships and not the physical changes in appearance. This difference primarily has to do with their mature age and not having a husband to please.

Changes in physical ability

This section addresses the struggle that chronically ill Saudi women encounter between their desire to fulfil their obligations and their physical inability to perform them. All participants, regardless of age and marital status, indicated that they wanted to perform their daily tasks and meet their social obligations, but were unable to do so because of the physical limitations imposed by several medical problems. At the initial phase of diagnosis, all of these women struggled to perform their normal duties but were soon overwhelmed by their physical inability to do so. The conflict between their desire to perform and their inability to do so, affects how they perceive themselves:

'I get up in the morning and I want to do a lot around the house: but I always find myself feeling tired and have to stop. It happens so fast. I must sit down, but I haven't really accomplished anything. Even though I have al-ragbah [strong desire] to do housework, I just don’t have al-kudrah [ability] to do it. I feel worthless.' Rogaiah (D-M)

All participants had to greatly alter their way of life in order to live with their illness while trying to fulfil their domestic obligations. These women found that avoiding strenuous tasks or altering activities were not always effective because at times even the simplest tasks became monumental due to various medical problems associated with ESRF and HD treatment. As an example, all the participants in my study have to avoid many activities that could damage the access for haemodialysis: graft or shunt. These restrictions caused by their chronic illness could be easily understood by their family members because they were visible. However, it is the so-called hidden conditions that were the most difficult for everyone to comprehend and accept. An example of a hidden condition is fatigue. Although effects of fatigue are real, the symptoms appear to be nonexistent because they are invisible. Thus, when a participant was unable to perform a task or complained about being tired, family members thought her non-performance or complaint had no medical basis. These ill women were made to feel lazy which led them to perceive themselves as being an outcast and a burden on their family:
'No matter what I do around the house, my brother’s wife doesn’t think it’s enough. She thinks I’m lazy because it takes me a long time to complete a household chore. When she sees me resting, she thinks I’m trying to avoid my responsibilities. I’m tired of explaining my illness to her and the rest of my relatives. I rather stay away from them than hear their complaints.' Lamia (D-MS)

Issues relating to fatigue, body pain and listlessness, were identified regardless of age and marital status. The effects of these conditions on the participants’ struggle to fulfil their obligations were similarly described.

When every participant compared these conditions with fellow-patients, they began to realize that fatigue (unlike tiredness) is a real condition related to their illness and not one caused by merely performing strenuous tasks. Once they understood that fatigue was not temporary, their perceptions about it changed and they no longer felt the obligation to push themselves unnecessarily. They no longer perceived themselves as being lazy or slow and began to reconcile themselves with their physical limitations even while performing the most ordinary household chores, e.g. sitting while waiting for the milk to boil:

'I can no longer stand the entire time I’m in the kitchen preparing food. It helps me to sit while I’m waiting for water or milk to boil, or even when I’m chopping vegetables.' Farida (D-W)

Body pain is a unique medical problem that overlaps with fatigue which all participants associate with fatigue. In fact, all these women considered body pain and fatigue as being the same. So when they were describing their body pain, they frequently interchanged terms, e.g., tiredness used to describe headaches, back pain and muscle cramps that disrupted them from performing their daily activities. As complained by Weddad:

'When my body aches, I feel tired and when I’m tired, my body aches. It’s all the same to me.' Weddad (D-M)

The temporary relief they received from over-the-counter medicine or herbal remedies enabled them to relax just enough to continue their tasks. Interestingly, the relief of pain seemed to decrease their sense of fatigue. Whatever they were able to accomplish gave them some self-satisfaction. Even if this positive attitude was only temporary, it was a respite after feeling downhearted for so long:

'I like to drink mint tea, it makes me relax and the aches go away for awhile. Then I am able to get up and do a little around the house. At these times, I actually feel good about myself.' Khairiah (D-W)

It is a false perception that one is no longer fatigued when there is temporary pain relief. This realization is made by all those participants who reported rushing to perform work once they were relieved of body pain, and then found themselves still unable to accomplish the task:
I'm so relieved when the pain stops, that I immediately begin to do my chores. But it doesn't take much for me to realize that my body is still too weak to accomplish anything.' Wajna (D-M)

Listlessness is another problem associated with the inability of all participants to perform activities. Although they perceive it as sleepiness, listlessness is related to the lack of energy and enthusiasm, and all participants regardless of age, described being 'sleepy' throughout the day. The nature of this problem disallows quick and spontaneous movement that is required to respond to immediate demands, e.g., attending to family member's sudden needs, especially, those of small children. Although their family members and acquaintances see them taking frequent 'naps', these women report that they are not really sleeping. They seem to be in a state of limbo where their eyes may be closed, but their minds remain alert. Regardless of how many 'naps' they take during the day, they complain that they are never completely rested:

'I lie down, but can't sleep. My family thinks I'm sleeping and expects me to be refreshed when I get up. But I feel just as sleepy and tired. I try to get involved with my extended family but it's still difficult for me.' Sohad (D-MS)

After they realized that listlessness was a part of their condition that would continue no matter how many 'naps' they took, they knew that they had to become more dependent on their family to help them perform their domestic obligations. However, asking for help made them perceive themselves as being useless:

'I don't like to ask my relatives for help around the house, but I have no choice. I feel I'm useless to my family; I just can't get myself to do it properly.' Eida (D-M)

The change in physical appearance and physical limitations impacts greatly on the emotional well-being of Saudi women with ESRF. When these women observe a decline in their appearance and experience deterioration in their physical ability, their doubts about the outcome of the illness cause them to fear the uncertainty of their future.

Changes in cognitive ability

There is a causal relationship between the physiological changes due to ESRF and the changes in various cognitive functions resulting therefrom. Chronic renal failure produces toxic waste in the blood which affects the patient's cognitive ability, such as: resulting in impaired judgements, difficulty concentrating and memory loss. Participants complained about how they found themselves in predicaments when they could not even remember to turn off the stove after cooking a meal, leaving a key in the front door or even forgetting the directions to their home when returning from the dialysis centre in a taxi:

'I find that I forget the smallest things, things that I do everyday. One day I even forgot the directions to my home from the dialysis centre. I was so embarrassed.' Hasina (C-D)
When they become confused, they begin to doubt the soundness of their memory and judgement; and they vacillate when making mundane decisions. Due to these cognitive impairments, all of these women, regardless of age and marital status, found themselves increasingly unable to make the simplest of choices in their daily life, thus, resulting in their constant state of anxiety:

'I'm always second-guessing myself when it comes to my young daughters. Sometimes I forget which one went with which relative and who is going to bring them back home. I never had these day-to-day problems before my illness. I know I'm not that old to be so forgetful, but I feel I have to go over the same things in my mind so I don't make mistakes. It makes me nervous.'

Feattoo (D-MS)

Their numerous concerns can result in a mental overload that results in a sense of insecurity as they encounter daily challenges. They are sometimes overwhelmed by issues such as taking a taxi to the dialysis centre or waiting for a relative to drive them; making the decision to take a young daughter to the dialysis centre or leaving her at home. Since these logistical problems must be dealt with everyday, these women continuously experience anxiety which impacts on their emotional and psychological well-being:

'I'm never sure of whether my brother who lives with me is going to take me to the dialysis centre or whether I'll have to call my cousin, who lives close by to go with me in a taxi. As soon as I'm up for the day I wonder about this and by the time I have to leave the house, I am confused and I feel my nerves are all pulled (tensed).'

Maimoona (D-MS)

These women lose their assertiveness and begin to defer to the opinions of relatives, regardless of whether they agree with them or not. Thus, the primary outcome of these cognitive dysfunctions is self-doubt; when they perceive themselves as being unreliable and not dependable. All participants described themselves as suffering from varying signs of depression: sleep disturbances, difficulty concentrating, and withdrawal from social activity. There were three extreme cases of depression reported by two married women who admitted to having had suicidal thoughts but never acted on them; and Sahar (A-MS) who reported to have actually attempted suicide. Thus, the severity of the impact of changes of physical appearance, physical ability and cognitive ability on the emotional and psychological well-being of these women is profound.

It can be seen that all participants face the reality of the changes that occur during the course of their illness. The impact of these changes affects their ability to meet their family's expectations and successfully perform family obligations. When they begin to regard themselves as failures within their roles and relationships, they adopt a negative self-concept and ultimately see themselves as being a burden to their family. At times when they feel more positive about themselves, they are more effective at performing their tasks and relating to their family. It is during these times that women are more likely to normalize their illness into their everyday life.
Fear of the uncertainty of the future

Fear of the uncertainty of the future is experienced by all participants. The unpredictable patterns of symptoms and conditions associated with ESRF are the source for great emotional stress regardless of age and marital status. Often, I observed their great discomfort when they were describing their fears of the future. When Awsal began to find difficulty moving her extremities and found her condition worsening, she began to dwell on the possibility of paralysis:

'I am already in a wheelchair and I pray that nothing else goes wrong. If I think too much about what may happen to me next, I get scared and start crying.' Awsal (D-M)

Participants began worrying about further losses in their functional capacities and exaggerated any sign of physical deterioration. For example, when Nariman (D-W) frequently experienced breathlessness due to fluid accumulation in her body, she perceived that she was dying from suffocation.

How physical deterioration and disability can impact on emotional and psychological well-being and further cause them to fear the uncertainty of the future is seen in the case of Tagreed (D-W), who lost complete mobility and had to resort to using a wheelchair. As she progressively lost function of her legs, she became more anxious until her nervous condition escalated to a state of panic. As she discusses her future during the interview and the uncertainty about her physical condition, her fear manifested itself in sweat and tears.

The impact of the uncertainty of the future on the ability of Saudi women suffering from ESRF can be clearly seen in the differences in perception between those participants who have already received a transplant that failed and therefore had to return to dialysis therapy and those who are still awaiting a transplant. The former group of women are no longer uncertain about the permanency of their disease and had begun to reconcile themselves with their illness. They no longer suffer from anxiety of the unknown because they have already experienced the entire process: finding a matching donor, undergoing surgery, waiting to see if their body accepted the transplant and finally accepting the permanency of their condition when the transplant fails. On the other hand, the latter group experience great emotional fluctuations ranging from hope to fear of the uncertainty of the future because they are still waiting for a possible transplant and do not know if a matched donor will be found or whether the transplant will be successful. Sohad whose transplant failed states:

'Since my transplant has failed, I no longer have to wonder about whether this illness is permanent. I now know that this wash (dialysis) will always be a part of my life and I pray to Allah [God] for patience for it since I have to live with it.' Sohad (D-MS)

Marwa who is still waiting for her transplant states:

'I still believe that once I have my transplant I will fully recover and return to my normal life. But there are times when I have doubts about this because I
know several friends (fellow-patients) who had to return to dialysis when their transplants were unsuccessful.' Marwa (A-S)

All women who have children (regardless of their age and gender) living with them, are obsessed about the possibility of dying and leaving them behind (within the context of dying from ESRF), which is discussed later in Chapter 10. To counter their fear of this particular uncertainty, they sought reassurance, about who would care for their children from their husband and male guardians.

Dallal, (D-D), is the only ever married participant in this study without children and Awsal (D-M), is the only participant whose children are all married. For these two women, rather than being compelled to think of young children they may leave behind, their only concern was about themselves. Thus, they have different apprehensions than the mothers who worry about the care of their young children. They are concerned about how their family will treat them if they become disabled; or who will perform their burial rites upon death. They speak to their sister and niece about these matters because they are younger and are expected to take care of them while they are alive; and also perform the pre-burial and post-burial Islamic rites upon death. They state that these matters occupy their thoughts and that they frequently seek reassurance from them:

'I have to always awassi [instruct a verbal will] my family to send me off in the right way [by Islamic ritual]; they have to do it when I'm gone, no one else but they can do it.' Dallal (D-D)

'I seem to repeat myself to my sister about taking care of me. I am always worried that she will forget that I need her more now that my health is getting worse.' Awsal (D-M)

This feeling of uncertainty about the future impedes the emotional well-being of Saudi women with ESRF.

Adapting to the illness

Although from an analytical viewpoint this aspect of making sense of ESRF cannot be considered to be the end of the process. This is because of the dynamic nature of being able to adjust to chronic illness which can alter each moment. The participants express how they are better able to accept their illness when they are successfully performing their roles and maintaining their relationships. But when they fall short of success, they revert to perceiving themselves negatively. All of them seem to indicate that their medical regimen and the length of time they have been ill has enabled them to incorporate ESRF into their every day life.

With time, all participants, regardless of age and marital status, begin to incorporate the illness into their life and become better equipped to adapt to it. The repetitious pattern of behaviour that is the nature of any routine helps to enable the patients to incorporate the illness into their daily life and perceive it as being normal. The medical regimen that they learn to adapt to includes: visiting the dialysis centre, and undergoing dialysis three times a week, constantly watching their fluid intake, weighing themselves before and after dialysis, and taking naps
several times a day. By repetitively fulfilling these various tasks, they are actually living with their illness without much thought of doing so. Thus, this process becomes more of a way of life:

'It was very hard for me at the beginning to fit my therapy into my life. I had to remind myself that today I had to go to the dialysis centre. But after a while, I didn't even think of it, it was a part of my day.' Fattoo (D-MS)

Living with the illness is a learning experience where they discover what is effective by means of trial and error, rather than always following a fixed prescribed method. Success at finding a new way that works for them, helps these women to regain some of their confidence, which in turn helps them to adopt a more positive self-concept:

'The doctor told me to watch what I eat and drink because I shouldn't take too many fluids. It's difficult to do when I'm always hot and thirsty. So a friend (fellow-patient) recommended that I suck on ice cubes rather than drink a glass of water. This helped me a lot.' Ghada (A-MS)

It is not only the repetitive patterns of behaviour of a medical routine and trial and error that eases the process of making sense of the illness, but the time factor that is also important when it comes to patients adapting to their illness. During their dialysis sessions, all participants become more aware that HD therapy is unlike any other form of treatment they had ever received; it is a course of treatment that continues throughout their life, unless they receive a successful transplant. It appears that the longer a participant receives dialysis, the more tolerant she becomes to its signs and complications and subsequently, is more able to adapt to them as a part of her daily life: Arwa who had been on dialysis for 14 months states:

'I find dialysis treatment extremely uncomfortable. I always feel like vomiting and I also suffer from back pain and itching.' Arwa (B-S)

Whereas Areej who had been on dialysis for four years, states:

'I find dialysis treatment moderately uncomfortable. I feel like vomiting and I also suffer from back pain and itching only on those days I receive dialysis.' Areej (B-S)

It is apparent from these descriptions that their perceptions about pain and discomfort changed as time passed and therapy continued. In response to my question on this issue, a Saudi doctor explained that their characterizations of the condition as 'moderate' uncomfortable are direct correlations to the length of time they have been undergoing dialysis, since their therapy had not changed in either duration or intensity.

Adapting to the illness is an ongoing process that fluctuates as these women constantly struggle to balance their medical regimen with their regular routine domestic activities. The difficulty in reaching this goal is also compounded by the impact of their condition on their emotional and psychological well-being. Yet, when they do meet a challenge successfully and overcome their fears of the
unknown, not only do they adopt a more positive self-concept, they also begin to perceive the illness as a significant part of their way of life.

Conclusion

This chapter explored how Saudi women suffering from ESRF perceive themselves with regard to the physical, emotional and psychological changes they experience as they attempt to make sense of the illness.

Initially, these women were unable to associate their symptoms with a chronic illness and therefore did not perceive themselves as seriously ill, but merely tired or strained from their daily domestic duties. Thus, they first had to recognize their illness and its implications before they could perceive themselves as being seriously ill.

It was only after recognizing the illness that they could begin to confront the gradual changes of their physical appearance, physical ability and cognitive ability. Living with the illness may be considered the most vital aspect in the process of making sense of the illness because it addresses how the participants' self-perceptions are shaped. It can be seen that all of the women in this study had the willingness and desire to continue to fulfil their family roles and obligations despite their physical limitations caused by the chronic illness. However, their continuous encounters with the debilitating effects of the illness and the loss of ability to function satisfactorily affected their emotional and psychological well-being.

Women with ESRF perceive themselves as being failures in their roles and relationships, resulting in a negative self-concept. In order to adapt to ESRF, chronically ill Saudi women attempt to balance their medical regimen with their daily domestic responsibilities. It can be seen that repetition, routine and time altered their perceptions about ESRF; what was once considered to be irregular is now perceived as normal.

These women's perceptions about themselves and their illness can vary daily depending on whether they have a good or bad day. As their self-perceptions fluctuate, their emotional and psychological well-being will change accordingly. Therefore, this process is ongoing and Saudi women suffering from ESRF feel they must persevere in their endeavours to adjust to their altered way of life.
Chapter Eight
The Importance of Religious, Medical and Economic Resources for Saudi Women with ESRF

This chapter analyses how support resources affect the quality of life for Saudi women suffering from ESRF, namely how religious, medical and economic resources enable the participants to manage their life. The focus of this chapter is the impact of medical resources and the lack of economic resources on quality of life of Saudi women in this study. (NB. Social resources are discussed in the following chapter). The participants' marital status, motherhood status (having children), income and their health condition, are the primary factors that influence women’s need for specific resources.

The support resources of the participants can be divided into three categories: al-dawlah [State], al-ahl [family] and al-maarif [acquaintances]. Each of these sources can be further divided into subcategories. Al-dawlah [State], through its agencies, the Ministry of Health and the Ministry of Social Affairs, basically provides medical and some economic resources. Al-ahl [family] consists of the al-usrah [immediate/nuclear], al-akarib [extended] from both the paternal and maternal sides; and al-arham [in-laws] representing all relatives by marriage (Table 4.1). Al-maarif [acquaintances] includes al-asdika [friends], al-jeran [neighbours], and ahl-al-Khair [benefactors]. Dependence on these sources is shaped by the socio-cultural norms of Saudi society which designates the family as the primary source of support for religious, economic and social resources; while acquaintances provide supplemental assistance in these areas (Figure 8.1).

In order to understand why individual participants depend on different family members, the dynamics of the Saudi family structure must be discussed. The differences found in support from the al-usrah [immediate/nuclear] family for Saudi women are based on their marital status: for single women, it includes their parents and siblings; for married women, it includes their husband and any offspring; while previously married women are treated as single women but may have the addition of offspring. The category of the al-akarib [extended family] includes grandparents, uncles, aunts and cousins for all women, with the addition of parents and siblings for married women. Under Islamic law, Muslim women are forbidden to marry their maharam [male related to the female by sanguinity or blood relationship], and therefore do not have to separate or cover themselves in their presence. Whereas, they are permitted to marry those individuals who are not maharam (such as cousins and non-relatives) and therefore must separate or cover themselves in their presence (Figure 4.1).

For the purposes of this study, the women’s quality of life is defined by the impact the availability or lack of resources have on their well-being. The concept of quality of life is a comprehensive one that entails the participants' ability to function effectively within their social milieu while adapting to limitations imposed by ESRF. It is reiterated throughout the narratives that the participants hope to preserve their quality of life as they attempt to integrate into their daily life the changes brought about by their illness regarding all aspects (religion, health, financial and social) of their life.
This chapter discusses three types of resources: religious, medical and economic; and the sources that provide them. When analysing the interview data, I identified these specific resources as being necessary for all participants to better manage their illness which may eventually provide them with a better quality of life.

Figure 8.1

Types of support resources and sources that provide them

<table>
<thead>
<tr>
<th>Sources of support</th>
<th>Support resources</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Religious</td>
</tr>
<tr>
<td>Al-dawlah [State]</td>
<td>Ministry of Health (MOH) JKC</td>
</tr>
<tr>
<td></td>
<td>Ministry of Social Affairs (MOSA) Welfare agencies</td>
</tr>
<tr>
<td>Al-aal [Family]</td>
<td>Al-usrah [Immediate/ nuclear family]</td>
</tr>
<tr>
<td></td>
<td>Al-akarib [Extended Family]</td>
</tr>
<tr>
<td></td>
<td>Al-arham [In-laws]</td>
</tr>
<tr>
<td>Al-maarif [Acquaintances]</td>
<td>Al-asdika [Friends]</td>
</tr>
<tr>
<td></td>
<td>Al-jeran [Neighbours]</td>
</tr>
<tr>
<td></td>
<td>Ahl-al-khair [Benefactors]</td>
</tr>
</tbody>
</table>

**NB:** (+) Support; (-) no support; (+/-) occasional support; and (*) fixed annual stipend
Religious resources

One of the most valued and most accessible resources that the participants have to aid them in managing their illness is their religion. All 50 participants, regardless of their age, shared similar attitudes when it came to religion. They were thankful for their religion and recognized the importance of holding tightly to Islamic concepts involving suffering, patience and reward. These women not only perform their religious ritual obligations, but they have incorporated their beliefs into every area of their life. Since Islam does not require women or sick individuals to practice religious duties outside the home, there is no stress in having to go to a place of worship or join a formal religious group. There were no constraints on this particular resource since the place of worship and the various religious obligations can be performed within the confines of the home. The women described how members of their family and acquaintances gathered at their homes to recite the Quran and pray together. They talked about receiving spiritual consolation when these informal groups sat together to discuss the hadith involving the ways that Muslims properly handle obstacles, setbacks and personal trials and tribulations. These religious discussions sometimes take place at formal gatherings held at the local masjids [mosques], but most of the discussions are with friends and neighbours in their homes:

'Wallah [I swear to God], if it is not my strong belief in Allah [God], I would have long ago lost my mind.' Sabra (C-M)

'Alhamdullilah [Thank God] for the strong faith He (God) gave to me in handling this illness.' Khairiah (D-W)

'When al-ahl [family] and al-asdika [friends] get together to listen to the stories of the prophets and how each of them suffered, I realize that Almu’min mubtala [true believers are tested through suffering] and that makes me feel better.' Buthainah (C-D)

'Through listening to prophet’s stories, I have come to believe that my illness is an ibtilaa min Allah [an infliction from God]' Nawara (B-S)

Listening to the adhan [call for prayer] over the loudspeakers from the local masjids while they are sitting in their homes or hearing it being recited in the dialysis centre while undergoing dialysis therapy, has a positive effect on their spiritual well-being. The following participants' comments illustrate the significant role religion plays in the management of their life:

'Listening to the adhan [call for prayer] is a blessing in itself. It comforts my heart and allows me to pray to Allah [God] to support me through the day.' Fattoo (D-MS)

'Sometimes I feel Allah [God] provided this adhan [call for prayer] in order to provide comfort to my heart and remind me to pray for strength and ability to carry on my daily obligations.' Basma (B-M)

It has been highlighted in Chapter 4 how the Islamic religion and culture plays a dominant role in Saudi society. Although religious support is provided primarily by family members and acquaintances, participants indicated that they have also
benefited from the religious lectures and literature provided to them on various occasions by other women. Since Islam is considered a way of life rather than an expression of an isolated occasion or celebration, all aspects of everyday life, no matter how small they may seem, are treated as a form of worship, i.e., what one eats and drinks, how one bathes and how one greets another person, to name only a few. Since religion is the one resource that can be found in abundance and is never depleted, these women feel they can always find spiritual solace as long as they adhere closely to Islamic values regarding suffering, patience and reward.

Medical resources

Since ESRF is a life-threatening condition where medical requirements are immediate and long term, medical resources are the most crucial for all participants. The Ministry of Health (MOH) is the only source that provides free medical resources that meet the participants' healthcare requirements. It subsidizes King Fahd Hospital which includes Jeddah Kidney Centre (JKC); the largest government subsidized kidney dialysis Centre in the Kingdom. Although there are other MOH hospitals that have dialysis units, they contain only three or four machines which are used mainly by in-patients. Six of the participants had been initially treated at these hospitals, but were subsequently transferred to JKC once they were discharged. Three other participants had received dialysis treatment at private hospitals, but were transferred to JKC because of the high cost of private treatment. They reported that costs for treatment in private hospitals were 1200SR (£163) per dialysis session; not including additional costs for medication. Thirty-six participants went directly to JKC for treatment because they were originally admitted to King Fahd Hospital; and the remaining five were transferred to JKC from hospitals in other towns.

The JKC is the only haemodialysis centre located in Jeddah. This proved to be a constraint on those participants who were transferred from hospitals that were located closer to their homes. Both distance and time became a constraint for 42 participants who had to travel to and from the dialysis centre three times a week for treatment. It took 38 women between 30 minutes and 1 hour and took 12 women 1-1½ hours to get to the dialysis centre by car. They hypothesize about how convenient it would be for them to either live within walking distance from the dialysis centre or close enough for a much shorter drive:

'I wish I lived closer to the dialysis centre where I don’t have to travel at least 40 minutes to get to the dialysis centre. May be I could have just walked rather than having to wait for someone to drive me every time I needed to go to the dialysis centre.' Afrah (B-M)

The participants complained of suffering from physical discomfort arising out of the lengthy time spent travelling to the dialysis centre:

'Because we live so far, it takes me more than an hour to reach the dialysis centre, by the time I get to the dialysis centre I feel my head is spinning.' Hiba (D-M)

'I hate that it takes more than an hour drive in the car to get to the dialysis centre, it makes my body ache.' Abeer (B-M)
'It takes me at least an hour just to reach the dialysis centre. So much time is spent just for going and coming from the dialysis centre. It is very tiring.' Sonia (D-W)

'I have to take this long trip three times a week for my dialysis, which makes me feel sick. I wish it was closer to where I live.' Sultana (D-W)

The JKC is the only facility that operates four haemodialysis shifts on a daily basis, six days a week. Unfortunately, therapy schedules arranged for the participants are fixed and most complaints lodged by the participants concern this inflexibility. Although the JKC administration tries its best to accommodate participants' time preferences, it is almost impossible to juggle four shifts to exactly meet all of their needs. There are times when a patient is able to exchange their time slot with another patient via the head nurse, but this is merely a temporary solution. There is no convenient solution for those patients who need to change their entire schedules from one shift to another. As Badia states regarding the difficulties with her dialysis schedule:

'You know it is very difficult to have these pre-set dialysis schedules; sometimes I have to change it either because something came up at home, or my husband who has to bring me to the dialysis centre is not available, although I had originally based my schedule to suit my family.' Badia (C-M)

Another participant, Rabha complains of her fixed schedule that is set for the early morning shift:

'It takes me a long time to get to sleep at night and when I finally fall asleep around five in the morning, I have to get up and get ready to be at the dialysis centre for my seven o'clock shift. I wish I could call the dialysis centre and change the schedule for the afternoon, but I can't; if I needed to do that I would have to schedule it ahead of time.' Rabha (C-M)

In order to get to their therapy sessions on time, relatives and acquaintances that have their own schedules, usually take the participants to the dialysis centre an hour or more before her scheduled dialysis session. They also pick participants up often very late. The participants complain how uncomfortable it is to spend these extra hours at the dialysis centre, especially because there is a lack of privacy and space to rest. Although participants expressed their gratitude for having the dialysis centre they do mention how the lack of certain conveniences at the dialysis centre, such as, private seating areas with cushioned seating, makes the entire process difficult and stressful. They report how they have to resort to sleeping on uncomfortable benches in the open hall:

'Alhamdullilah [thank God] the dialysis centre is good for the treatment, but it does not have any place where we or our young children can stay in; we also have to be careful when we are sitting, there is no real privacy. It's like you are in a hallway.' Fatin (A-M)

'Wallah [I swear to God], I even fall asleep for one hour before my husband can pick me up...it is not comfortable, but I have no choice, I can't wait inside (the unit), nor can I go home until my ride comes.' Mana (B-M)
'I think all of us patients and even our children have spent many hours in the waiting area; waiting, talking, praying, playing or taking short sleeps.' Sahar (A-MS)

The insufficient number of nurses has had another adverse effect on patients' medical care. The participants expressed their concern about the lack of availability of nurses and according to the head nurse there is a (1:4) nurse-patient ratio at the dialysis centre. Even though the participants do get to see the nurses while they are being connected to and disconnected from the dialysis machine, there is rarely sufficient time to discuss medically-related matters with them because the nurses must quickly move on to other patients. The nurses themselves state that although they want to spend more time with their patients, they are under severe time constraints: As Saboora, a Saudi nurse states:

'All the nurses working here would like to give more time to each patient, but we are already under pressure. Each nurse is in charge of four and sometimes five patients in each session, plus the other things she has to do.' Saboora (Saudi nurse)

Hadia, another Saudi nurse, states that:

'Sometime patients request the same nurse, but it is hard, because nurses rotate all the time.' Hadia (Saudi nurse)

Another adverse effect on their medical care is the difficulty the participants have in communicating their concerns to expatriate nurses who do not speak Arabic. Approximately 85% of the nurses in JKC are non-Arabic speaking. Although these nurses are technically trained to obtain the vital data, i.e., blood pressure, temperature, etc. from their patients, they are unable to understand their verbal accounts. Thus, non-Arabic speaking nurses must obtain the services of Arabic speaking nurses. This solution is not always a practical one because of the aforementioned time constraints on nurses. Dawlat complained:

'Some of the nurses can't understand me; I have to tell either nurse Saboora or nurse Hadia (Arabic speaking nurses), to be my translators.' Dawlat (D-W)

While Dallal illustrates how she tries to deal with the problem:

'I only talk to her (a non-Arabic speaking nurse) if I feel something is urgently wrong, or I'm going to get sick...I usually point at what I really need.' Dallal (D-D)

The narratives reveal the importance for participants to have medical information as they experience different symptoms of their condition, e.g. cramps, shortness of breath. At the initial stage of their illness, they received medical information from medical personnel. But as time passed, new questions and issues arose concerning their physical changes, benefits of using traditional remedies and alternative approaches to the daily management of their condition. Fellow-patients became the primary and sometimes the sole source of this type of information. While some of this information may have helped participants, the doctors expressed concern
that unless the patients tell them what remedies they are using, consequences jeopardizing their treatment may occur:

'Fellow-patients have become an important part of my life. Since I became ill and started visiting the dialysis centre, I feel close to them and I feel I can ask them about the different things, like the general weakness, numbness, cramps that I feel in my body. I feel they know what I'm talking about and can help by telling me what they did when a similar thing happened to them. I remember the time I had a severe rash, I called my friend (a fellow-patient) on the phone and she told me not to worry it also happened to her when she first started her dialysis; and she also told me to wrap it in a warm towel and ask the doctor for an ointment when I go to the dialysis centre. That was a great help, I did ask for the ointment when the doctor came. Alhamdullilah [thank God], some of these fellow-patients share their experience with me. At times, I feel this is the only way I can be immediately reassured that this is part of the dialysis process or just that it is normal.' Rehab (D-D)

All women in the study had thought about their condition and the inconvenience it causes. They have suggested that their life could be made easier and more comfortable if certain home health care programs were implemented by the State. They mentioned that having nurses visit them in their homes to provide dialysis would ease their anxiety about the never-ending transportation issue. They even expressed their need for doctors or nurses to visit them on their 'off' days (days when they do not receive dialysis, but suffer from side-effects of their condition), since they are unable to go to the dialysis centre due to economic or time constraints on their family. During conversations about what things would make their daily health care management easier, some of the participants wistfully stated that they could use someone to prepare their meals to suit their restricted diet:

'There is no one in my home who can properly help me when I suffer nausea and dizziness. I always wish I could call a doctor or nurse to come over and check on me.' Hasiba (D-M)

When I disclosed to Hasiba that there were home health care programs implemented in other countries, she exclaimed:

'...that would be a dream come true; I wish they (home health care programs) were here, too.' Hasiba (D-M)

All participants continue to struggle with inconveniences despite the availability of free medical treatment and dialysis therapy. Each day, they experience physical discomfort and emotional anxiety over practicalities mentioned above. Overall, these adverse effects mount daily, further diminishing their quality of life.

**Income**

The interview data identifies income, transportation and accommodation as the three areas of economic resources that have a major effect on the quality of life of the participants. These economic resources will be discussed in this and the following two sections. These three elements are intertwined and cannot be
discussed as separate entities: participants' primary source of income depends on their wali-al-amr [legal guardian] who is the head of the household with whom they reside: father, husband, brother, uncle or son. While transportation to and from the dialysis centre depends on the accessibility of income provided by the head of the household.

For women with ESRF the greater the availability of all three of these economic resources, the easier it is for them to manage their practical tasks; while the lack of these resources places serious constraints on the quality of life of the participants and their families.

Income can be divided into two categories: household and personal income. As stated above, the former is provided by the head of the household and is spent on family necessities. Saudi women belonging to a low economic status, like nearly all of the participants in my study, do not have direct access to this income because it is the head of the household who is responsible for paying the bills. Participants depend on the head of the household to make necessary purchases for the family and allocate funds for specific needs, e.g. transportation. Forty-six women interviewed for this study, regardless of marital status, were not in paid employment, with only four women retired on health grounds. Forty-three out of the 50 women do not have any personal income; only the remaining seven participants received any form of personal income: inheritance, retirement benefits on health grounds or any other economic assistance provided on a regular basis by al-akarib [extended family] members, ahl-al-khair [benefactors] or social welfare agencies. These women explained that they had to use this personal income for transportation expenses; and whatever balance remained was then spent on their families. They never seemed to have enough personal income to spend on personal items for themselves.

Out of the seven women receiving some form of personal income, three women (single, married and widowed) had been employed as teachers prior to the onset of ESRF and now receive monthly retirement benefits on health grounds between 3000-5000SR [£406-678]; one participant (married) who was previously employed as a seamstress also receives 500SR [£68] monthly retirement benefits on health grounds. Only two participants (widowed) receive a shared inheritance that involves a monthly rental income from tenants in their building. These monies vary depending upon occupancy and they reported that they receive monthly funds of up to 2500SR (£339). The one remaining participant, a widow receives regular funds from ahl-al-Khair [benefactors] which varies from month to month. It is important to reiterate that these seven participants emphasized that their personal income was spent on transportation and household necessities; not on personal items for themselves:

'I can't use my money (personal income) on myself; I had to help my husband (ex), he had so much responsibility on his shoulders. So I spend whatever money I get on transportation, groceries or things for the house.' Lamia (D-MS)

Arwa, previously a teacher, also comments that the personal income she receives from her retirement benefits on health grounds is spent on this expenditure rather than on personal items:
'My personal income is now always spent on transportation or household material. I never use it to buy any stuff for me anymore.' Arwa (B-S)

As mentioned above, only one woman receives funds from benefactors on a long term basis; however, all except nine participants occasionally receive assistance from Ahl-al-khair [benefactors]. Ahl-al-khair, are private citizens who bear no blood ties to the people they help. They are individuals who recognize their religious obligations to the sick and needy and try to assist them. They can be anyone who is informed that a person needs some type of assistance (money, goods or services) and then volunteers to provide it. They only learn the identity of the participants from those who know their personal circumstances. This relationship can either be a short term or long term one.

The form of economic support contributed by Ahl-al-khair [benefactors] is occasional funds, goods and services. Most of the time the resources donated to these women are not in the form of cash, but instead are groceries, household goods and appliances, etc. Some of the participants explained that there were times when the benefactors even asked for utility bills in order to make direct utility payments; but the women would have preferred cash, so that they could decide for themselves how the funds should be spent:

'Wallah [I swear to God], it would have been a thousand times better for me if Ahl-al-khair [benefactors] had given me the money instead of the stuff they got me. I can't tell them (benefactors) to give me the money and let me choose what we really need. But you see what they regard as important to my family; may not be what is really needed for me or my children.' Tagreed (D-W)

The women also reported that like Ahl-al-khair [benefactors], welfare agencies also provided them with groceries and other goods. They noted that these agencies never asked them what they needed but gave them whatever goods were available at the time. These provisions did not last very long because they were given only once a month. The women also asserted that they could not depend on Ahl-al-khair to be a constant source of support since help is not provided on a consistent basis. They specifically point out that funds may not be given at the most appropriate time to enable them to purchase needed goods or to pay outstanding bills.

Unlike support systems in the West, there are no State funded programs of support that provide disability benefits or attendance allowances for women with ESRF. During my research, I ascertained that MOSA provides an annual stipend of 3000SR (£406); to all ESRF patients. In addition, the King provides a makrama [special gift] of 1200SR (£163); to these patients every Ramadan. Although the participants expressed their appreciation for these supplemental monies, they did acknowledge that the amount does not cover the expenses they incur throughout the year:

'The 3000SR my family gets from the 'affairs office' (Ministry of Social Affairs) is for sure very little compared to what me and my family needs.' Hasna (C-M)
In addition, all participants report that they occasionally receive supplemental monies from *al-akarib* [extended family] and *al-arham* [in-laws], but this is of a lesser amount and given intermittently.

**Transportation for dialysis**

Transportation is vitally important for all participants' medical management for without it they cannot get to the dialysis centre and receive dialysis treatment. All participants, regardless of marital status and age, required transportation because they live at least 30 minutes away from the dialysis centre, which ruled out the possibility of walking. But transportation should also be considered another economic element for the purposes of this study, since its cost is a major financial strain for every participant.

Although single participants did not dwell on this issue, because they had very little or nothing to do with family finances, they were still aware of the financial stress it caused their families.

All 42 of the ever married participants complained that transportation to and from the dialysis centre was their largest expense. It did not matter if they had access to a family or friend's car; money had to be spent on petrol. When they relied on a taxi service, they had to pay for the fare. The fare is based on mileage and since all of these women live at least 30 minutes drive away from the dialysis centre, minimum fares could be estimated between 20-40SR [£3-6], one way. For the twelve participants who live more than an hour away from the dialysis centre, their transportation costs were far greater. It is not surprising to find in the data that the largest amount of absentees from therapy sessions come from this latter group of participants, who live more than an hour away from the dialysis centre.

The frequency of visits to the dialysis centre is another factor that further depletes their economic resources. Thirty-five of these 42 women needed transportation to visit the dialysis centre three times a week, and they reported they paid a minimum of 120-240SR (£17-34) each week on transportation expenditure. Since all but two women from these categories had attended the dialysis centre between two and ten years for dialysis sessions, it is obvious that transportation has been their greatest expenditure.

More importantly, a lack of funds can produce a life or death situation. Thirteen participants did not attend their dialysis sessions at least twice a month simply because they could not afford the fare. Eight of them reported that as a result, they ended up having to go to the emergency room due to complications of their health condition. As Abla states:

'A great part of our daily spending goes to transportation; so when my husband does not have an income (out of a job) at that time, I can't even go to the dialysis centre for my dialysis. Several times I had to go to be taken to the emergency room for dialysis, because I had to wait until we could afford the transportation money.' Abla (D-M)

Issues relating to the difficulty these participants have in arranging transportation due to socio-cultural constraints will be discussed in Chapter 9.
Accommodation and changes in living arrangements

Accommodation is another important economic resource affecting the participants' way of life. The type of accommodation available to them is affected by their marital status, and ESRF influences their marital status. Independence, authority and privacy are essential factors directly related to whether they live in their own home, whether they move back to their parents' home or whether they move in with extended family members.

Eight participants out of the 50 were single and therefore never have moved out of their parent's home. In these cases, the father is the primary source of income for as long as he lives. Data reveals that in four cases where the father is deceased, the older brother who resides with the mother has taken over the father's financial responsibilities. These single women did not experience a change in their housing situation when they got sick, thus their living arrangements were not affected.

All 42 of the participants who are ever married emphasized the importance of both income and accommodation as critically related to their quality of life. Interestingly, they consider these economic resources to be more crucial in terms of their overall well-being than medical resources. This may be due to the fact that half (21 out of 42) of these participants, due to a change in their marital status, have had to also change their accommodation and primary source of income. These 21 women comprised nine widows, five divorced and seven women who were still legally married but separated from their husbands who had deserted them (Table 8.1). Since separation and divorce are culturally frowned upon in Saudi society, the fact that 12 are separated or divorced and only 21 remain married indicates that Saudi women with chronic illness such as ESRF experience a high likelihood of marital breakdown. Although 21 participants are currently married, they are constantly mindful that the possibility of change in their marital status still exists because their husband may take another wife.

<table>
<thead>
<tr>
<th>Marital status</th>
<th>Stayed in their own home with an older son</th>
<th>Moved back to parent's home</th>
<th>Moved to married son's home</th>
<th>Moved to married brother's home</th>
<th>Moved to married uncle's home</th>
</tr>
</thead>
<tbody>
<tr>
<td>Separated</td>
<td>2</td>
<td>4</td>
<td>0</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>(7)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Divorced</td>
<td>1</td>
<td>1</td>
<td>0</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>(5)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Widowed</td>
<td>2</td>
<td>1</td>
<td>2</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>(9)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total n=</td>
<td>5</td>
<td>6</td>
<td>2</td>
<td>4</td>
<td>4</td>
</tr>
</tbody>
</table>

Table 8.1
The accommodation of previously married participants (n= 21)
The main distinction amongst the 21 participants who no longer live with their husband, is between those participants who had to move out of their homes and back with a male guardian (16) following marital separation or widowhood and those who were able to remain living in their own homes (5) (Table 8.1). The 16 women who had lived and raised their children in their own homes were now required to revert to the social status of 'single' women who must live in the home of a male guardian. There are socio-religious as well as economic reasons for this. Socio-religious custom in Saudi Arabia requires male guardians to accept responsibility to maintain their female relatives when a husband dies or is no longer co-resident because of divorce or separation. In addition, it is economically not feasible for them to maintain a separate abode. Therefore, these women do not have a choice except to move-in with a male guardian, since they cannot afford to pay for their own accommodation. As seen in Table 8.1, five of these women were able to maintain their own home because they either had personal income available or inherited a house; and also had at least one older son (above the age 16) who could act as their male legal guardian.

**Separated women**

Seven separated women did not actually live with their husbands (although only two identified themselves as being separated). Four of these participants had to move back to their parents' home and relied on either their father or brother for primary economic support; and one had to move into her married brother's home and relied on him for her primary economic support. The remaining two separated participants continued to live with their children in their own homes which they had inherited from their own fathers. The latter's unusual living arrangements was only permitted because these two women had older sons of viable age (defined in Saudi society as age of responsibility, over the age of 16) living with them. However, they had to depend on their brother and uncle for primary economic support, since their husbands had abandoned them.

**Divorced women**

Among the divorced women (5), one had to move back to her parents' home and relied upon her father for primary economic support, while one had to move in with her married brother and relied upon him for her primary economic support. Two had to move in with their married uncles and relied upon them for primary economic support. The remaining two separated participants continued to live with their children in their own homes which they had inherited from their own fathers. Yet, she still depended upon her brother and uncle for primary economic support. Although all of these women had children, two of them who had to move in with their brother and uncle were allowed to keep their younger children (12 years or less); while the older sons (13 years of age) stayed with their fathers. Dividing the children based on gender and age has to do with separation of the sexes within a household where female cousins reside. In these two cases, the women had to move into a household where nieces were present, and since their older sons were not a mahram to the nieces', they had to live with their fathers:

\[\text{After my divorce, I had to move out of our home and go to live with my married brother and his family at their home. I took 4 of my younger}\]
daughters (less than 12 years old) with me, but could not take my older sons (more than 13 years) because my brother has young unmarried girls in the house. Three of my sons are living with their father. ' Hayat (C-D)

Two of the divorced women whose children are living with them, complained that they had detected drastic changes towards them and their children in the attitudes of their host family after they moved in with their guardian. Prior to their divorce, relatives did not criticize their children's misconduct or upbringing, because the father was present and discipline was considered to be his role:

'You know things only changed after my divorce, when I and my children had to move-in to live with my married uncle and his family. Before that they always respected me and cared about my feelings a lot.' Rehab (D-D)

Because of their situation, divorced women living with relatives are always mindful and feel they must remain vigilant when it comes to the whereabouts and the activities of their children. They complained about having to constantly supervise their children 12 years or less in order to prevent them from stepping out of bounds, since their children no longer have their own space for recreational activities. They always monitor their children to prevent them from going into the kitchen for snacks and warn them against entering their relatives' bedrooms:

'Wallah [I swear to God], I was always hard on my children to avoid any conflict with my brother or his wife. Everyday I have to remind them that we are like guests here, and we must be very careful not to be a further burden by our problems or our fights.' Hayat (C-D)

These divorced women voiced their dismay at how their relatives ignored how their own children failed to comply with certain traditional customs, such as, removing their shoes upon entering the house or sitting higher (on a chair/sofa) than an adult who is sitting on the floor. They noted that their relatives' children who exhibited sullenness when being reprimanded by an adult were not corrected, while their children were always being chastised for any slight infraction:

'Unfortunately now my children were being blamed for every little thing...it was as though they were being watched or that someone was waiting for them to make a mistake so that they would be picked on. Their children may be the ones that must be watched or checked much of the time for their misbehaviour, loudness or even at times rudeness, but that always seems to go unnoticed as though it was the right behaviour.' Hayat (C-D)

Only one divorced woman Dallal who did not have any children did not share these types of concerns. In fact, she considered being 'childless' as a blessing in disguise:

'It was so much easier for me to make this move alone; and that not having children turned out to be a blessing after all'. Dallal (D-D)

She further comments that:
'When hearing other's problems it makes my problems seem much lighter. When I heard a fellow-patient complain about the difficulty she is having after losing her husband, moving into a relative’s home with her two daughters, and the misery she and her daughters are facing, I thank Allah [God] that I have no children with me. Otherwise my situation would be miserable for my children too; if not worse.' Dallal (D-D)

Interestingly, the other two divorced women did not share these experiences because one lived in her own home and the other lived with her parents.

**Widowed women**

Among the widowed women (9), one had to move back to her parents' home but had to rely on her brother for primary economic support. Two had to move in with their married brothers and two had to move in with their uncles relying upon them for their primary support. Two participants had to move in with their married sons after their husband's death; while two women stayed in their own homes which they inherited from their own fathers, and lived with their children who included an older son (Table 8.1). Similar to their married and divorced counterparts, all widows depended upon a brother or uncle for primary economic support.

Four of the widows who lived with their guardian together with sons older than 13 years, reveal that they reluctantly send them outside to play or to study under a street lamp to avoid criticism or confrontation from their relatives. Some of these women have admitted to being harsh on their older sons when feeling undue family pressure. They express feelings of guilt and shame, knowing that they have contributed to their sons' emotional distress. Farida admitted that her son had run away twice, because he felt unwanted by her and harassed by his uncle. Her son had interpreted his dismissal from the house as a rejection by his mother; whereas, she was merely trying to avoid further arguments:

'My son whose 13 years old ran away from home twice; he said that I always took my brother's children's side over his, and that I always blamed him, even if it was not his fault. He does not understand that there was nothing I could do.' Farida (D-W)

Four widows who live with their guardian along with their daughters older than 12 years reported that they noticed how differently their daughters were being treated from their sons. They ascribed this difference to the fact that their daughters performed certain household chores for their female relatives. Their daughters were also able to provide personal care for their mother and childcare for their younger siblings. Their contribution was a relief for female relatives residing in the same home. However, the participants were sensitive to how their daughters' contribution to the household was being abused. Although their daughters were not usually confronted with accusations or the harsh language that their sons had to endure, the participants were of the opinion that their daughters were being treated as servants working 'to pay for their room and board'. They resented that their relatives never showed any appreciation for their daughters' domestic work, but instead criticized it for not being up to standard. They felt that their relatives never considered that their daughters had enough responsibilities in just taking care of their mother and their own younger siblings. They strongly felt that their
daughters were being overburdened with various household chores that could easily be performed by other female family members. Wesal who had to move in with her uncle and his family states:

'she (her uncle's wife) would always ask my daughter to bring things for her or to prepare something... even though her daughter, whose almost the same age as my daughter, would also be sitting in the same room... it is no coincidence... only yesterday her daughter and mine were watching television when she asked my daughter to help her prepare something in the kitchen.... My daughter said that 'I did not finish the ironing yet... and why don't you tell Asma (uncle's daughter) to do that instead of me'... She (uncle's wife) ignored her and repeated 'just hurry up, because I want you to help me'... My daughter ran to the room crying... I could not do anything except tell my daughter we have to share with the housework, as we are sharing their house.' Wesal (D-W)

Maisa who lives with her uncle described how her discomfort and anxiety worsens when her married daughters visit her. Since the male relatives and in-laws (uncle's sons and sons-in-law) are not supposed to see or socialize with her married daughters, her married daughters must go to the participant's bedroom during their visits. If her married daughters bring their spouse and children for a visit, it becomes too crowded and the participant feels embarrassed that she cannot properly host her personal guests. These constraints in effect keep her daughters from visiting her more frequently. She has expressed deep sadness for being deprived of relationships with her married daughters and grandchildren:

'My daughter and her children have to always check to see what would be a good time to come and visit me without being in anybody's way... like no other guests are present or my uncle's family do not have other commitments.' Maisa (D-W)

The main difficulties experienced by the 15 out of 16 previously married participants who had to move in with their guardians involved their children (one divorced woman had no children). These women were under constant pressure to treat their children in what they perceived to be a harsh manner in order to avoid criticism or confrontation from their host family. This caused a rift between them and their children, especially their sons. Participants with older daughters, who contributed to household chores, were sensitive to how the host family seemed to overburden them with extra duties. For these women, the change in accommodation caused an erosion of their mother-child role and relationship which triggers deep feelings of guilt and shame, and adverse effects on their quality of life and well-being.

**Implications of moving in with extended family members**

There were similarities between the separated (5), divorced (4) and widowed (7) women who had to leave their own homes in terms of their descriptions of the effect of their changed marital status on their personal life. All of these women recited numerous instances illustrating the challenges and hardships they encountered once they moved to the homes of their male guardians. They described their previous life as married women living with their husbands and the benefits associated with that marital status. They state how they had previously
been basically independent when making personal choices and only had to defer to their husbands when making major decisions affecting the entire family. They headed up the domestic side of their households and assumed all domestic duties as they made decisions as the primary care-giver. They stressed that while they were living in their own home, they had privacy and personal space.

A change in their demeanour was easily discerned when widowed and divorced women began discussing their loss of status, because of moving to live with a male guardian. Their grief not only expressed the loss of their husband, but their loss of self-identity and way of life as well. They complained that they are no longer treated as independent women who are capable of making decisions for themselves and their children. Instead, they have to accept their guardian's decisions, whether they agree with them or not. They find themselves no longer in a position to manage household duties, since they are overseen by other women living in the household. They have very little if any privacy because they now have to share their living space with their children and other members of the extended family. They express how they feel more like a guest, rather than a member of the household and that they no longer consider their residence their 'home', but rather a place for lodging:

'I tell my daughters that this is gismatna [our destiny]; it is written for us. We are not in our home now, we must let go with anything; we must accept our situation.' Wesal (D-W)

The main distinction among these previously married participants is how differently the family perceives these groups of women. Widowed participants are seen as 'victims of fate' where the death of their husband is an act of Allah [God] and therefore cannot be blamed on the woman. Her children are now considered aytam [orphans], a category of people seen as requiring special tenderness and sympathy. The participants who fall within this category report receiving special sympathy and patience from their family and acquaintances:

'My brother expressed his commitment to me and my children when he said, 'Don't worry; you and these ayatam [orphans] are now my responsibility. May Allah [God] give me the ability to do this'. ' Nariman (D-W)

On the other hand, the participants who are separated or divorced are considered to be part of the problem, rather than a victim. Certain members of the extended family may blame them for the divorce and treat them as the troublemakers. Participants quoted family remarks blaming them for their divorce:

'I feel when they say something like, 'you should have been more patient' or 'you get angry too quickly'...it is like they are blaming me for the divorce.' Hasina (C-D)

'My aunt always tells me 'you should have been more tolerant',.' Hayat (C-D)

'My relative once blamed me for the divorce, she said, 'Look at Rasmia, your cousin; she has to keep up with a much worse husband than yours'. ' Dallal (D-D)
"So many times my aunts blame me for the situation I'm in; like it was my fault. They always tell me 'you should have been more patient, for your children's sake'." Rehab (D-D)

In Saudi society, children of previously married women usually live with their father and/or his family, because the father is seen as responsible for the economic support of the children. However, among my sample, most of the participants' children were living with them instead of the father or his family. All the separated, widowed and two of the divorced participants had been left with the responsibility for raising and supporting their children. They now have to depend solely on the host family's household income to support themselves and their children. They are sensitive about their place within the host family household and try their best to compensate their relatives by struggling to help with domestic chores despite their physical limitations. It has been difficult for their host families to understand why the father or his family did not assume legal responsibility towards their own children; and they constantly complain of the additional financial burden they must bear. These women state that the host family either wants their children to go to their fathers or his family; or they want them to reunite with their ex-husbands. These unfortunate circumstances force these women to live in very stressful environments.

A striking difference is found between these women and the remaining five divorced/widowed women who were able to stay in their own homes with their children because they had an older son. They portray a different picture when describing their living conditions. They still have their privacy in their own homes and have maintained authority over raising their children without constant interference from their relatives. Thus, their independent way of life has not changed despite the change in their marital status. However, they remain financially dependent on their extended family.

**Conclusion**

This chapter has examined the relationship between the availability of various resources and the quality of life for Saudi women with ESRF. There are no constraints on religious resources for these women, since Islam makes it easy for them to worship and fulfil their religious obligations within the confines of their homes.

Participants receive adequate medical care at the dialysis centre, provided by the Ministry of Health, so there are no constraints associated with the availability of medical resources, such as medicine or therapy. Instead, the key constraints are linked to other issues relating to their condition, i.e., distance and time to travel from the dialysis centre, the fixed therapy schedule, lack of certain conveniences such as adequate waiting areas that have privacy for those patients who have to use it for long periods of time, and the insufficient number of nurses and communication difficulties with non-Arabic speaking nurses. These problems related to the dialysis centre may not directly concern their treatment; nevertheless participants complained that they did have an impact on their health and well-being because they were constant causes of stress and anxiety that affected their quality of life.
It can easily be asserted that it takes more than medical treatment to sustain the quality of life for these women. The specific constraints referred to in this chapter are not temporary ones, but are as long-term as ESRF. This has to do with their permanent need for adequate economic resources. Over a lengthy period of time, their limited income has been further stretched to accommodate their chronic illness, e.g. transportation costs. Since the constraints on income are due to the socio-economic reality of the women and their family and acquaintances, all of them have a dire need for financial funds.

Accommodation is another extremely important material economic resource for the 21 previously married participants. Since almost half of the previously married participants became separated or divorced after the onset of ESRF, it may be concluded that the rate of divorce and separation amongst these women is a direct result of their chronic illness. Sixteen women had no choice but to leave their home and move in to live with a guardian, experiencing a drastic change in their quality of life. They no longer had the authority over themselves and their children and everything they did or said was being judged by their host family. Clearly, the importance of accommodation is emphasized by these women because it directly affects their independence, authority and privacy. The relatively high proportion of separated or divorced women amongst participants with ESRF (12 out of 42 ever married women are either separated or divorced after the onset of their illness) suggests that many Saudi women with chronic illness will suffer a disruption in their quality of life as a result of a change in marital status.
Chapter Nine
The Importance of Family Support for Saudi Women with ESRF

This chapter examines how Saudi women with ESRF rely extensively upon their family network as the primary source for social support. Social support includes two types of support: inter-personal relationships and practical support from family members (Figure 9.1). Practical support must be further divided into domestic support that is primarily provided by female relatives and non-domestic support that is primarily provided by male relatives. Acquaintances are merely a supplementary source that provides occasional practical support. This chapter also examines how limited family support diminishes these women's quality of life.

![Figure 9.1](image)

Social support and the sources that provide it

<table>
<thead>
<tr>
<th>Sources of social support</th>
<th>Types of social support</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>(a) Inter-personal relationships</td>
</tr>
<tr>
<td></td>
<td>Domestic</td>
</tr>
<tr>
<td><strong>Al-usrah</strong></td>
<td>+</td>
</tr>
<tr>
<td>[Immediate family]</td>
<td></td>
</tr>
<tr>
<td><strong>Al-ahl</strong></td>
<td></td>
</tr>
<tr>
<td>[Family]</td>
<td></td>
</tr>
<tr>
<td><strong>Al-akarib</strong></td>
<td>+</td>
</tr>
<tr>
<td>[Extended Family]</td>
<td></td>
</tr>
<tr>
<td><strong>Al-arham</strong></td>
<td>+</td>
</tr>
<tr>
<td>[In-laws]</td>
<td></td>
</tr>
<tr>
<td><strong>Al-asdika</strong></td>
<td></td>
</tr>
<tr>
<td>[Friends]</td>
<td></td>
</tr>
<tr>
<td><strong>Al-jeran</strong></td>
<td></td>
</tr>
<tr>
<td>[Neighbours]</td>
<td></td>
</tr>
<tr>
<td><strong>Ahl-al-khair</strong></td>
<td></td>
</tr>
<tr>
<td>[Benefactors]</td>
<td></td>
</tr>
</tbody>
</table>

*NB: (+) Support; (-) no support; (+/-) occasional support*

Through many years of tradition, Saudi family structure (Figure 4.1) and sources of social support (Figure 9.1) were culturally shaped to define family responsibilities towards its members. The uniqueness of Saudi family structure can be found in its static nature despite many changes that have occurred in other aspects of society, i.e., the economy and education. Socio-cultural norms of Saudi society dictate that *al-ahl* [family] is the primary source for social support. Since their family is the main source of social resources, Saudi women depend heavily
upon their family to help them manage their life. It is only when *al-ahl* [family] becomes unavailable to provide practical support that participants turn to *al-maarif* [acquaintances] for assistance.

Since all participants regardless of age, marital status, motherhood, income and health condition, require social support, any limitations on family network are considered to be just as serious as medical and economic limitations. This attitude has to do with the importance placed upon families and their relationships. However, the research highlights that it is economic constraints on family members and acquaintances that also have a great impact on the availability of social support for women with ESRF. Financial limitation places great strain on the availability of social support which results in a decline in the quality of life for these women.

**Inter-personal relationships**

All Saudi women in this study regard their inter-personal relationships with family members as being just as essential to sustaining their quality of life as their access to medical and economic resources. The inter-personal relationships that seriously affect these participants include: blood-related marriage and blood-related in-laws, which are often severely tested in cases of divorce or separation.

**Blood-related marriage**

Marital status is the main characteristic that influences relationships between family members. In particular, when regarding kin-marriages (consanguineous), social relationships are intricate for both married and divorced/separated women. Being married to a cousin can be vital to the type of support women with ESRF can expect to receive. More responsibility to care for a chronically ill niece is placed upon in-laws who are also uncles and aunts, and their responsibility continues regardless of a change in her marital status.

In Saudi society, the highest percentage of kin-marriages is between first cousins. Although this tradition is changing in modern society, 30 of the 42 ever married participants in this study report that they married their first cousins. This ratio of about 2/3rds of cousin marriages is typical in Saudi Arabia. Most of these women consider marriage to their cousins as a resource in itself. Since the spouses' family (in-laws) is also their family, they do not feel embarrassed asking their mother-in-law or sister-in-law to come over and help them with household chores now that they are physically limited by ESRF. Also, domestic relations are easier and more convenient since these in-laws are in fact their aunts and cousins who are expected to help in these matters. Thus, intermarriage is considered to be a blessing in Saudi society because both families are considered as one, benefitting from each others' resources. These 30 participants claim that it is a relief that their in-laws are actually their blood relatives, since there is a greater familiarity between these women and their aunts and cousins that does not exist with in-laws who are not blood-related:

"Alhamdullilah, [thank God] my arham [in-laws] are also my akarib [extended family - aunts and uncles], so I don't feel ashamed to ask them for help with housework and other domestic chores. Even though they know me well, I
have to keep my dignity in front of them, because they are still my arham [in-laws]. So, I try to do my best when they are around.' Sultana (D-W)

It is interesting to note the apparent distinction between blood-related in-laws and in-laws by marriage when examining the narratives of the other 12 participants who are not married to their cousins. They discuss how uncomfortable they are around their in-laws because they do not want to reveal their physical weaknesses resulting from ESRF. These women are afraid that their mother-in-law might think they are a failure in marriage, so they are hesitant in asking her to come over and help with menial tasks. Sumaya who is not married to a cousin states:

'I'm always careful in front of my mother-in-law. I avoid asking her for any help; and try to manage everything by myself when she is around, because I don't want her criticizing me or thinking that I'm an unfit wife or mother.' Sumaya (D-M)

The participants in blood-related marriages do not feel it necessary to strictly adhere to Saudi custom requiring a daughter-in-law to treat her in-laws with great deference. Although this custom may promote respect amongst the in-laws, its formality may not be viewed as conducive to producing comfortable inter-personal relationships.

Divorce and blood-related in-laws

While participants may extol the virtues of being married to their cousins, their narratives reveal the constraints that can be found within this type of marriage. These constraints often impede the quality of life for these women because marital disputes become much more complicated when both sides of the family are blood-related, i.e. a father-in-law is actually an uncle or a sister-in-law is actually a cousin. These women have discovered the true implications of these multi-faceted relationships if they have a falling out with their husband. If the disagreement is serious or if it leads to separation or divorce, these women have reported that they lose a large segment of their family support and can no longer depend on their extended family or in-laws for economic and social resources.

The most serious problem with this type of marriage is relayed by Dallal (D-D, childless), a participant who found that close family relationships were marred once she was divorced by her cousin. Her husband/cousin subsequently married a second wife in order to have children. The complication arose out of their relationship to her; Dallal and her husband were both cousins to his second wife. He remained married to Dallal until the birth of his first child with his second wife when his economic constraints made it too burdensome for him to maintain two households. When I questioned her about the possibility of both wives sharing one household she responded that 'I feared being neglected or treated as a servant.' Since he could no longer afford to support the participant, he chose to divorce her. Although the primary reason for divorce was a financial one, Dallal continued to blame her illness for her divorce since it was the main cause of her infertility. She reported that after her divorce, she had to move in with the only available male guardian, her uncle who happened to be the father of the second wife. Complications arose out of the dual role her uncle played: that of an uncle to the participant and that of the father-in-law to her ex-husband, which made her very uncomfortable. Problems developed when the uncle's daughter voiced her
unease at the participant being present when she and her husband came to visit. She feared that her husband would be reminded of his previous marriage to their cousin. Thus, the aunt no longer wanted Dallal to live with them for fear of reconciliation between Dallal and her ex-husband:

'I should not tell you this, but I just want to show you that sometimes marrying a relative could be a nikma [curse] not a nama [blessing], like we always think. But what can I do? Aldarura laha ahkam [common phrase meaning necessity has its laws], I don't have another choice. If it was not for my need, I would not choose this living arrangement, especially under such circumstances where my relationship with my uncle's wife is really not that great; but my uncle is wali amri [legal guardian] and my hawjati louh mura [phrase meaning: my need for him is bitter].' Dallal (D-D)

Thus, when her uncle's daughter comes to visit with husband and child, Dallal does not partake in the social gatherings and prefers to remain in another part of the house to avoid any personal embarrassment. These gatherings take place on a weekly basis and the participant is always faced with the harsh reality that she will never have a family of her own. Dallal reports feeling great emotional distress, low self-esteem and isolation from her family:

'It is always hard when every day I see my cousin (now participant's ex-husband's wife) happy and caring for her children who might have been your own one day. Imagine I even baby-sit for them when she leaves her baby here and has to go somewhere with her husband (participant's cousin and ex-husband), and I help in preparing meals for their dinner when they come back. I never join them when they come over, but most of the time I hear their voices in my room.' Dallal (D-D)

Other examples illustrate how kin-marriages between first cousins may weaken family ties thereby diminishing social support and the quality of life for women, who are separated or divorced.

Rehab (D-D) reported that she lives with her uncle because he was the only guardian who could support her. The bad feelings that her uncle's wife subsequently heaped on her occurred after Rehab's brother divorced her uncle's daughter, who had to move-back in with her father, Rehab's uncle. Rehab's sister-in-law/cousin no longer wanted to live with her husband because he had economic difficulties and could not support her anymore. Their divorce forced her to move back to her father's house where the participant (cousin/ex-sister-in-law) also resided. The uncle criticized his nephew/ex-son-in-law for not being able to properly take care of his daughter. Now he had to not only support his divorced niece, but also his divorced daughter. The uncle's wife hinted that if it were not for the participant's additional expenses, he would have been able to help their daughter and son-in-law settle their debts. I observed how uncomfortable Rehab was sitting in her uncle's house relating her story to me: she furtively looked around the room and lowered her voice as she complained of constantly being reminded of her brother's shortcomings.

Two of the nine widowed women had to move in with their uncles following the death of their husbands/cousins. Both of these women state that their reason for
moving-in with them was on account of the guardian relationship between uncle and niece and not the in-law relationship they had during the life of their husbands. Although they did not report the negative experiences that their divorced counterparts had experienced because their prior relationship with the dead spouse had not been vilified, they still had difficulties with their uncle's wife who expected their children to undertake more of the domestic responsibilities:

'My uncle's wife expects my daughters to take care of all household chores for her; it is like there is no one else in the house but them. Even when their married sisters are visiting us, she finds things for them to do. Sometimes I tell her to wait till their sisters leave because I know my daughters want to stay with them or play with their young children. But most other times I ask my daughters to go and see what needs to be done; just to avoid any argument in the family.' Wesal (D-W)

Traditionally, Saudi society has encouraged marriages between cousins due to economic and social benefits. As already illustrated, members of the same family are usually not reluctant to share their resources with one another, thus, it is easy for close-knit immediate and extended families to combine their assets for the benefit of the entire family. Inter-personal relationships are a resource in and of themselves where these women can find comfort and security in sharing the same values as their husband's family. However, the separated or divorced participants complained how their new marital status strained family ties and caused rifts amongst their cousin's parents and themselves. Yet, their relationships with their guardian/in-laws still remain an indispensable source for social support.

Domestic support

Another key aspect of social resources is practical support, which includes domestic and non-domestic support. Domestic support includes personal care, household chores, and childcare; non-domestic is defined as support including transportation, escorting, running errands and shopping, which will be discussed in the following two sections.

According to Saudi tradition, female relatives and friends are expected to assist in domestic care, which is the reason domestic responsibilities are placed solely on females. Consequently, participants always turn to their female relatives and friends for domestic assistance and when discussing their sources of social support, emphasis is placed upon the relationships amongst the female members of al-ahl [family] and al-maarif [acquaintances]:

'I never noticed that I always go to my sisters and other female relatives for help with household chores and with my children. I guess it is because this kind of assistance can only come from them. Men are never expected to help in these matters.' Badia (C-M)

All participants, regardless of demographic characteristics, depend first on those female family members who live within the same household for domestic support. These relatives comprise both the immediate and extended parts of the family. When these family members are unable to cater to their needs, the participants
state that they request assistance from their female extended family and in-laws who live outside of the household. When no members of the family are available, the participants then turn to their female acquaintances:

'My usrah [immediate family] always help me with the household chores; but it is not enough. Sometimes I seek the help of my akarib [extended family]; but most of the time they themselves are busy or unable. So, I always lean on my usrah [immediate family]. It isn't fair, but there is nothing I can do. I only ask for necessities.' Hasna (C-M)

An overlap can be seen in the types of resources and assistance provided by both the family members outside the household and acquaintances (Figure 9.1).

It can be seen how significant a role female relatives play when support involves taking care of the personal needs of a chronically ill woman's body. Forty-four participants reported that there were days when they required assistance in bathing and grooming due to various physical ailments; yet on other days they were able to take care of themselves:

'Sometimes I have to ask my aunt or sister to help me bath, when I feel dizzy or tired. But some days I can take care of myself, so I don't bother them.' Mana (B-M)

The six participants who suffered from physical disabilities, such as, immobility or visual impairment, required constant assistance with personal care:

'I can't stand while having a bath, I'm afraid I'll slip and fall. So, I always ask my daughter for help.' Eida (D-M)

Thus, personal care depends on the health condition of the participants, which can change daily regardless of age, marital status and motherhood.

Unlike personal care, domestic activities that include household chores and childcare require frequent assistance from members of the family. Childcare not only includes babysitting while mothers are at the dialysis centre, it involves the entire range of maternal care for children: bathing, visits to the paediatrician for sickness, vaccinations, etc. Marital status and motherhood are crucial factors when determining the need for household chores and childcare, e.g., women with children require more assistance from their family than do their single counterparts.

Single women

A distinction can be made between those single women who are in age group (a) (younger age 24-28) and those who are in age group (b) (older age 29-35) (Table 7.1). This distinction is based on the family's original expectations of the younger women prior to the onset of ESRF. Single women in age group (a) were between the ages of 14 to 17 years old when inflicted with ESRF, were still in school during this time, and they depended mostly on their mothers and older sisters for domestic support. Rather than being occupied with daily household chores, they were expected to do school assignments. Even though these younger women were
in their twenties at the time of this study, they were stuck in some sort of time warp, where their family still treated them as if they are young girls. In the minds of their relatives, these women are still of an age that is considered to be suitable for marriage so they are still considered to be teenagers. They report that they did occasionally perform light cleaning and assist in serving guests; but were never required to prepare meals or do heavier chores:

'Sometimes when I feel fine, I usually try to help in tidying up the house or folding the laundry with my mother or sister.' Rana (A-S)

'I try to serve the tea and coffee when my aunts and cousins come to visit us.' Bayan (A-S)

Once they started their dialysis treatment, these younger women dropped out of school and stayed home. They report that since their mothers had to provide them with personal care and took pity on them, their domestic responsibilities never increased. When their mothers had to escort them to and from the dialysis centre for treatment, their siblings' had to assume a greater share of domestic responsibilities, including childcare for younger siblings. They complained how sisters resented them for being the reason behind their sister's increase in domestic responsibilities. This resentment further exacerbated stress and tension within the household:

'I feel my sisters now are annoyed because I don't help around the house. I even heard my sisters complain to my mother many times, pointing at me and saying 'Why can't she do it? She did not do anything the whole day'. They say that I just sit and watch television the whole day or as soon as I come from outside (dialysis), I just go to sleep.' Marwa (A-S)

Unlike single women in age group (a) (24-28 years), single women in age group (b) (29-38 years) stated that even though they also live at home with their parents and other unmarried siblings, they are not relieved of domestic duties. While the younger women were in school at the onset of ESRF, the older ones had already been helping their mother perform domestic chores, childcare and care for elderly members of their family. So, their families expected them to continue helping after they had become ill. This expectation is mainly due to the families' misunderstanding of ESRF. Since the participants come and go to a dialysis centre where the family is prevented from seeing them hooked up to a dialysis machine, they fail to understand the seriousness of the illness. They assume these women can fulfil their previous roles and duties, because they are neither being hospitalized for periods of time nor undergoing surgical procedures. These older single women complained that their relatives consider them lazy when they express tiredness and slowly respond to others' requests. These criticisms are hurtful and lead to further separation between the participants and their family:

'Even my aunt once told me, 'maybe you need to help a little in the house, your sister already has a lot and your mother herself is not well'. Sulafa (B-S)

'Stop watching television, come and help me'. Ruba (B-S)

'Don't be lazy and finish what you started'. Areej (B-S)
In this study, the older single women (group b) are the only adults living at home with their elderly parents. They explain that although the domestic chores are supposed to be shared amongst all the female siblings in the family, those who are married and live outside of the home carry less of the burden, because they now have their own family responsibilities. Those single women who have only male siblings living at home end up being the sole caregiver of elderly parents within the household. These single women must turn to their extended family for assistance, because they not only have to care for their elderly family members, as well as brothers that still reside at home, they must also care for themselves and their own condition. These older single women commented on how their family's expectations, coupled with misconceptions about ESRF, have placed undue strain on them:

'Ahli [my family] thinks I'm still the same person I was before: taking care of my parents, the guests, everything in the home and even babysitting their children at times. But I'm not the same, my energy is not the same. I now need someone to care for me. I need them to see that I'm not just being lazy or tired. I'm really physically exhausted with every little effort I make.' Arwa (B-S)

'Akaribi [my relatives] may be willing to bring over cooked dishes, tidy up or do the shopping, but they will not do the more difficult daily chores dealing with the ironing or heavy cleaning of bathrooms and kitchens'. Nawara (B-S)

The apparent discrepancy in how family members treat the younger and older single participants arises out of their different expectations of them. These original expectations seem to be permanently set at the age these women were prior to the onset of ESRF. The younger women are still treated as if they were young girls without any domestic responsibility; while the older single women who had household duties prior to the onset of the disease, are still expected to perform these duties regardless of their illness. Their situation is further complicated by the fact that the older single women have elderly parents who cannot assist them; instead they need help themselves. Thus, these participants are required to care for their elderly parents even though they themselves are frail. What may appear to be insensitivity on the part of their family members seems to primarily stem from their misconception about the nature of ESRF. They fail to adapt their expectations according to the reality of chronic disease and the restrictions it imposes on the physical ability of these women.

Married women

Unlike single women, married women are the primary care-giver whose family has grown accustomed to them providing the bulk of domestic support. They explain how their roles and relationships as wife and mother shape family expectations that differ from their single counterparts. They reveal how it is not only difficult for them to relinquish this role despite their weakness and illness; it is also difficult for their husband and children to adjust when they have to rely upon outside assistance from extended family members:

'I find myself wanting to do the things I used to always do, but I fail to complete any task I was accustomed to doing previously. Most of my work
has to be divided in order to get it done. Some of the things, like cooking, have to be done everyday and you can't serve half cooked meals.' Basma (B-M)

'I can see it is difficult on my husband who is not used to taking care of me. I was always the one who took care of him, the children and the house. Now he sees that I can't do half the things I used to do around the house and he has to get used to it and live with it; until Allah [God] finds another way.' Wajna (D-M)

'The chores would have been already done but I needed some help, because I could not do them by myself. So I have to leave them for my aunt to complete for me.' Weddad (D-M)

Although married women have a daily routine to follow, they require their extended family members to compensate for their inability to perform domestic activities. The completion of married women’s routine domestic tasks depends on the availability of female family members, most of whom live outside their household.

Previously married women

Unlike their married counterparts, previously married women are not confronted with the same problems of trying to find domestic support from female relatives who resided outside their home. Since 16 out of the 21 previously married women are now living at their guardian's home, they are no longer the household primary care-giver. They only have to share some of the responsibility for household chores. The most important benefit that they were able to identify after moving in with other relatives following the change in their marital status was having at least one female relative at home who can assist or provide them with childcare and supervision when they are at the dialysis centre:

'When I hear other fellow patients worrying that they could not find anyone to leave their children with, I count my blessings that I have akarib [extended family] at home that I can depend on.' Wesal (D-W)

Motherhood

Motherhood is another crucial factor when determining the need for assistance with household chores and childcare. Gender and age of the children are also pertinent when determining the need for assistance. It is only the female members of the Saudi family who provide domestic care and not the sons (Table 9.1). Daughters under the age of 12 are not as helpful as older ones. Thus an ever married mother, who is childless or only has very young children or boys, requires more assistance from her extended family members. However, motherhood can have a great impact on the participants' quality of life if they can depend upon their daughters who live with them for domestic support.
Table 9.1
Number of ever married participants with daughters who provide domestic support

<table>
<thead>
<tr>
<th>Marital status</th>
<th>Only with daughters 12 years or less</th>
<th>Only with daughters 13 years or more</th>
<th>With daughters 12 years or less and 13 years or more</th>
<th>With married daughters</th>
</tr>
</thead>
<tbody>
<tr>
<td>Married</td>
<td>10</td>
<td>14</td>
<td>5</td>
<td>9</td>
</tr>
<tr>
<td>Separated</td>
<td>3</td>
<td>3</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Divorced</td>
<td>4</td>
<td>1</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Widowed</td>
<td>1</td>
<td>7</td>
<td>0</td>
<td>5</td>
</tr>
<tr>
<td>n=</td>
<td>18</td>
<td>25</td>
<td>7</td>
<td>14</td>
</tr>
</tbody>
</table>

NB. The number of ever married participants with daughters who provide domestic support do not add up to the total number (n=42) since some of these participants fall into more than one category.

**Women only with daughters age 12 years old or less**

The one 'childless' divorced participant and the 18 participants who only have daughters 12 years or less living with them complained of having less domestic support within their household than their 25 counterparts who have daughters 13 years or more living with them (Table 9.1). This is because the latter group has daughters who are able to regularly help their mothers with domestic support. The challenges are greater for mothers with daughters 12 years or less because they must seek out female relatives who are both able and willing to provide this demanding type of care, especially when they attend the dialysis centre which takes about six hours per day, usually three times a week. Since these mothers solely depend on family members who may not live in close proximity to their homes, in cases of emergency, they must seek the help of a neighbour:

'You know taking care of the children is not only taking care of them at home or when I go to the dialysis centre, or making food for them; it involves the entire care that involves children. Someone has to bathe them, take care of them when they are sick, take them to the doctor... when they are sick or to be vaccinated.' Badia (C-M)

'I depend on myself and my family for all the house chores, taking care of the children, running errands, transportation...every thing. But sometimes al-feran [neighbours] also help; like the time when my son fell and wounded himself with the broken glass and he was bleeding. I had no one with me, so I knocked at our neighbour and asked them to take us to the emergency hospital.' Buhainah (C-D)

Women prefer that their relatives come to their home to provide childcare, but instead, their relatives prefer that the children are brought to them for their convenience. But this proves to be an added burden. Fatin (A-M) describes that
when she requests her sister to come over and provide childcare so she can go to the dialysis centre, her sister suggests that she bring the children over to her house instead. This suggestion proved to be more burdensome for her since she was barely able to find someone to take her directly to the dialysis centre. She wondered how she would get someone to first take her to her sister's house, drop off the children, take her to the dialysis centre, pick her up, then pick up the children and finally take them all home. Fatin found that what seemed to be a viable solution for her sister was exasperating for her. However, she failed to realize that her sister had similar difficulties in travelling and leaving her own children alone at home.

**Women with daughters age 13 years old or more**

Twenty-five participants have one or more daughters aged 13 years or more living with them (Table 9.1). These daughters have been raised to assume the role of surrogate mother when needed. Their mothers must depend upon them for domestic support before requesting additional help from other female relatives, because the family expects these daughters to fulfil this role. Therefore, these participants are reluctant to seek assistance from female relatives living outside of their home, even when their daughters become overburdened with childcare and domestic responsibilities. However, this may disrupt the schooling of their daughters because of the necessity of caring for their younger siblings, while their mothers attend the dialysis centre:

'I feel sorry for my daughters. They always have to do all the household work. But I can't ask my sisters or cousins to come to my house, because they'll wonder what my girls are doing and criticize them.' Afrah (B-M)

A major challenge is introduced when participants do not have adult female relatives living within the same household or married daughters living in a household of their own who are able to provide assistance. Then they have to resort to the help of their young daughters who live with them (regardless of their age) for most of the domestic support. These mothers express feelings of guilt for 'depriving their daughters of a social life.' Although they desperately need their daughters' services, they still believe that they are being unfair to them because eventually their daughters will marry and have to continue to fulfil their domestic obligations for their own husband and children:

'You know my young daughter has learnt to iron her father’s and brother's thobes [man's long garments], something I myself felt tiring even when I was well. She is too young for this work, but this is our life. I just pray to Allah [God] to reward her with a better life in the future than the one we have now. I hope she marries someone who can provide her with someone to do things for her, just so that she can relax. I know she is overworked, but I'm too sick to do the ironing or run around after the younger children all day long.' Hasna (C-M)

On the one hand, daughters who reside with the participants are a great help to their mothers by relieving them of the pressure to seek help from their extended family members who lives outside their home. On the other hand, these women feel sad that they are depriving their daughters of their youth by relying heavily on
them for domestic support. This situation causes inner conflict and adds to the stress these women already experience with chronic illness.

**Women with married daughters**

The 14 participants who have married daughters are reluctant to seek their help because they live in their own household with their own family obligations (Table 9.1). They are fearful that their married daughters will either become resentful towards them or become too tired to satisfy their own family needs. They are sensitive to their daughters' own personal circumstances because they themselves were also married and had children at a young age. These women understand the difficulties of running a household and do not want to become another burden for their married daughters:

'I have two married daughters, but I feel each one needs help herself. The oldest daughter has a son who has an infection in his chest (asthma) and she is always running to the doctors with him. She sometimes wants my help, like leaving him with me when she has to go somewhere or leaving her other daughter when she needs to sleep in the hospital with him. Of course, sometimes I cannot provide that. My other daughter has difficulties with her husband, and she herself has to care for his family who is always present in her house. Sometimes when I need for her to come, her husband is either out or doesn't agree to bring her.' Rabha (C-M)

In attempts to relieve their married daughters from helping them, participants seek assistance from other family members who live outside the home:

'I know if my married daughters lived close by it would have been much easier for them to come and help me around the house. They have their own problems: who will bring them or who will open the door for their children when they come back from school? That's why I have to ask my other female relatives who live closer to come over and help.' Awsal (D-M)

**Summary**

Several factors influence the types of domestic and childcare support women with ESRF require. The women's health condition was the main factor determining their need for personal care. All women in this study managed their own personal care; but occasionally, they required assistance when their health condition worsened. Constant support for personal care was needed for those few who had physical disabilities. Marital status and motherhood are the other factors that determine the need for domestic support, such as, household chores and childcare. All of the women with children needed assistance from their female relatives and acquaintances. Those who had female relatives residing within their home felt fortunate because of the convenience; but others had to rely upon female relatives who were not always available to support them due to personal circumstances. Although, women who had to move in with members of their extended family had help that was readily accessible because there were other female adults living in that home, they generally suffered emotional distress because of their living arrangements, as discussed in Chapter 8. On the whole, it can be seen that family support is extremely important for Saudi women with chronic illness.
Non-domestic support

Non-domestic support for women with ESRF includes transportation, escorting, running errands and shopping. In Saudi society, this type of support has to be provided by men, therefore male members of the family are the primary source for non-domestic support. Women express that the accessibility of a mahram [males related to the female by a certain degree of sanguinity], i.e., father, brother, uncle, son, nephew of viable age (age of responsibility, over the age of 16) who resides with them at home, are the most valuable source for the management of their non-domestic affairs. This attitude has to do with a deep-seated reality that is embedded in Saudi tradition that requires male relatives to manage all family affairs that occur outside the home, i.e., shopping for food and personal items, and refilling the drinking water containers and gas cylinders used for cooking. No chore is considered too petty for Saudi men to handle if it relieves women from going outside of the home and interacting with strangers. Without their male relatives carrying out tasks outside the household, women cannot perform their domestic duties. Women themselves are accustomed to waiting for their male relatives to go and get groceries, gas, etc. It is only due to their condition associated with ESRF that makes this custom an inconvenience for the women in this study. They report that by the time male relatives accomplish these errands, they may feel too unwell to be able to fulfil their domestic responsibilities. These women are always concerned whether items are available while they still have the energy and strength to prepare meals or perform household chores:

'If there isn't anyone available to do things for us (grocery shopping), I have to wait until there is someone to do it. I can't send my daughters out to get the grocery, so sometimes we may wait till the next day.' Fatin (A-M)

'Whether I or my daughters need to get anything from the store in order to cook, we have to wait until there is someone available to do it. We have to do it around his (her husband's) schedule and he does it when he can. Every day I realize there are several things left incomplete from the day before because there was no one to get the stuff we needed.' Sabra (C-M)

Regardless of whether a participant is single, married, separated, divorced or widowed, she must depend upon a male relative to perform non-domestic tasks. The only difference is that the woman’s marital status defines the relationships with her male relatives who are likely to perform these tasks. In the case of single participants, it is the father or brother who is usually relied upon; for a married participant, it is their husband or older son; for a previously married participant, it is her older son, brother, father or uncle. The previously married participants reveal that they first ask those male relatives whom they have the most authority over to run errands for them, i.e., their son and brother, before asking the others. When none of these male relatives are available, all participants, regardless of marital status, report how they must refer to the male extended family members, i.e., nephews, cousins and in-laws. When all else fails, they request their acquaintances to ask their more distant male relatives for assistance in the areas of transportation, running errands or shopping:
'I give the money to my female neighbour or sometimes one of the fellow patients at the dialysis centre and ask her to ask her husband or other male relative to get the things I need from the shop or what my children want.' Abla (D-M)

Having access to transportation is the most important resource for carrying out non-domestic responsibilities by male relatives. Limited income that prohibits buying a car, paying a driver or paying for taxi service is a major constraint on the ability of male relatives to run errands, shop and escort participants to and from the dialysis centre (see Chapter 8). Participants report that their male relatives regularly postpone their non-domestic responsibilities due to these constraints and therefore at times these women have to wait until the only car in the extended family is available before they can perform their domestic chores:

'Sometimes it is the issue of not having enough money; sometimes it is the problem of having only one car that has to be shared by two or three of my al-akarib [extended family], depending on their need.' Maimoona (D-MS)

'I have to wait till my husband can get the money. We need another car, but it will be some time before my husband can buy them (her older sons) one. Things are under a very tight (economic) condition now.' Hiba (D-M)

'Although I know my brother is responsible for taking care of me, I'm ashamed to ask him for transport money when he is already having money problems. It is not like I'm asking for it to spend on frivolous things.' Farida (D-W)

Since the most important purpose for transportation is to get these women to and from the dialysis centre on time to receive dialysis, tardiness or unavailability of male relatives threatens participants' health. These women have reported waiting great lengths of time at the dialysis centre, before and after treatment, on account of their male relatives having to run errands for other members of the family. As was stated, many times their family has to share the car amongst different members of their extended family. They complain that waiting for lengthy periods of time before treatment is not just an inconvenience but a health problem, because it causes them anxiety which in turn affects how well they tolerate dialysis. Also, waiting for lengthy periods of time after treatment weakens their physical state, and they are exhausted by the time they reach home. When treatment or health is negatively affected, quality of life is adversely impacted for these women:

'Wallah [I swear to God], I need treatment from the waiting. I wait for an hour, sometimes two before my dialysis sessions begin. I feel my body and my head can't take it anymore. At least when I'm having my dialysis I can lie back, but it is hard to do that when your body is already tired from sitting several hours.' Waseela (C-M)

This section has discussed the need for non-domestic support provided by adult male family members (including teenage boys as young as 15 years). But when these men are unavailable and the participants are in dire need of someone to perform the various non-domestic tasks, such as transportation and escorting, they must resort to using young boys. In these cases, the age of responsibility for males can be as young as 12 years. Participants who have sons of this age reported that
the main constraint is waiting for their sons to get out of school, so that they could run errands or shop. However, when these women have to take a taxi, their young sons had to escort them to the dialysis centre. If participants were scheduled for morning dialysis hours, their young sons simply skipped school for that day. Obtaining a taxi proved to be a monumental task for their sons because many of these women live in out-of-the-way locations which lack easy access to the main road. As a result, their sons have to walk along convoluted paths to reach the main road where the taxis pass and by the time they get back home to pick up their mothers the cost for the ride has increased.

Those ever married participants (13) who do not have sons 13 years and over, may have to be escorted to the dialysis centre by female relatives living in the same household who can accompany them in a taxi or in a friend's or neighbour's car. Since it is permissible for women to accompany other women outside the home when necessary, women are also an invaluable source for the participants as long as they live in the same household. Participants explain that when these female relatives are unavailable to escort them, they must seek any available female relatives, friends, neighbours, and fellow-patients who live outside their household. Yet the pervasive concern expressed by these women is that their female relatives and acquaintances face similar practical challenges and transportation difficulties as they do. Like the participants, these female relatives must wait for their sons (who may be in school) or husbands (who are at work) to take them to the participant's home. Even if they have transport, they still have their own family responsibilities to take care of before the children get home from school. Some of the participants stated that there have been times when their female relatives have had funds for a taxi service, but still could not visit them because husbands or fathers forbade them to travel unescorted with a strange man (taxi driver):

'It is not easy, finding someone from ahli [my family] or maarif [my acquaintances] to take me around. They themselves face the same everyday issues that I have to deal with. Who will take me? Who will stay with the kids or wait for them when they come from school? With whom will I come back?...money...time...all these things they must consider. Wallah, Wallah [I swear to God repeated twice], it is not easy at all.' Tagreed (D-W)

These accounts reveal how the tradition of having to use male relatives for the provision of non-domestic support can prove to be a major constraint for the participants. This cultural tradition that restricts women's activities to the private sphere of the home and obliges men to perform all tasks in the public sphere outside the home, can be seen as an obstacle to their domestic management as well as to their medical regimen that requires them to visit the dialysis centre three days a week. However, these issues remain unresolved because it is part of Saudi tradition that women remain dependent on male relatives for practical support, which involves mothers' activities outside the home, i.e., shopping. Daily non-domestic responsibilities are shared amongst all adult males in the family. Therefore, the participants are constantly worrying about the logistics of when and who to ask or rely on. This causes them great anxiety and tension:
'Every night before going to bed, I have to check who will take me to the dialysis centre so I can either wake them up in the morning, or call on the phone to remind them again of my appointment.' Khairiah (D-W)

'Although my life depends on these dialysis sessions, I can't schedule in advance who will take me; I have to work it out based on who can, who may or who will.' Nariman (D-W)

When participants became ill with ESRF, age, marital status and motherhood dictated their need for domestic and non-domestic support. In Saudi society, the division between domestic and non-domestic support is based along gender lines for traditional cultural reasons. Female family members provide domestic support because they are allowed to be with the participants in their private quarters and are expected to help perform household chores; whereas the male family members are delegated to provide non-domestic support because they have the mandate to drive and perform all related tasks outside the home.

Conclusion

This chapter recognizes that access to family-related support resources for Saudi women with ESRF is just as crucial, if not more so in some ways, than the religious, medical and economic forms of support that were discussed in Chapter 8. Unfortunately, access to family-related support can be easily overlooked due to its private nature; especially in Saudi society where privacy of family and its relationships is considered to be paramount.

These women related how their chronic health circumstances have placed both a financial and social burden on their family members who belong to a low economic status. This increased burden negatively affects both their inter-personal relationships and practical support that their family is expected to provide them. They disclose the extent to which the unavailability of family-related support has on their ability to manage their illness and adjust to their new way of life. Their emotional well-being is jeopardized when they are not supported by their inter-personal relationships; and their daily activities are restricted as well as their medical regimen disrupted when practical support is unavailable. Thus, the lack of family support and its daily ramifications ultimately diminishes their quality of life.
Chapter Ten
Disruption of Family Care-giving Roles and Relationships due to ESRF

This chapter examines the factors that disrupt the various roles and relationships of Saudi women with ESRF, and the nature and extent of this disruption. It explores the impact of these disruptive factors on the emotional well-being of these women. Emotional well-being depends upon companionship, comfort, encouragement and reassurance. These particular features are integral in maintaining positive roles and relationships.

All of the women in this study have multiple and varied roles and relationships depending upon their marital and motherhood status. The different relationships they are involved in, such as, wife, mother, sister, and daughter, are characterized by varied sets of expectations. In turn, these expectations define the obligations and responsibilities of that role. In Saudi society, women not only have several roles to play, each role having as much importance as another and carrying with it a set of responsibilities that are expected to be fulfilled, they are constantly faced with the challenge of balancing their obligations. In the face of this challenge, strong inter-personal relationships with family and acquaintances are vital; but when this type of support is inadequate, it is very difficult for women with ESRF to sustain their varied roles and relationships. Thus, this challenge becomes unduly burdensome when in order to maintain a semblance of normality, these chronically ill women must depend upon their family to fulfil their roles.

As dependence on family members increases over time due to ESRF, various factors arise that can disrupt these women's roles and relationships. This results in their sense of loss of control over those aspects in their life that define who they are within the family and society.

The factors that sabotage traditional Saudi women's roles and relationships include: 'lack of communication and social participation', 'loss of marital intimacy', 'loss of domestic authority in the home', and 'loss of privacy'. Ultimately, these disruptive factors result in the woman's loss of control over aspects of life that have significant meaning for these women. The impact of these disruptive factors on roles and relationships depends on the participants' marital status, motherhood and age.

Lack of communication and social participation

Lack of communication and social participation generally disrupts the roles and relationships of all participants with ESRF. Since this illness is both physically and mentally debilitating, these chronically ill women find it difficult to engage themselves in family events. Nevertheless, their family expects them to become actively involved. Family expectations place undue burden on these women, who often find it much easier to avoid communicating their true feelings to their relatives and forego participating in family activities.

The main distinction between the eight single women and the other 42 participants in this study is that the single women are not primary care-givers, but instead are
the recipients of care within their family. This distinction is a crucial one in that their roles as a daughter, sister and aunt did not fundamentally change on account of their illness. It was only in their personal relationships that changes occurred, for example, it can be seen regarding their relationships with acquaintances. Single participants use their fellow-patients as their primary source of friendship; whereas, married and previously married women use them as a secondary source, because they still have their female relatives and friends to confide in.

Age is a factor that only has an impact on single women. Among single women, these specific distinctions can be seen between the age group (a) (24-28 years) (younger) and age group (b) (29-35 years) (older). First, the former are less responsible for domestic chores, because they have other siblings residing within the household for such assistance. The latter, however, must bear more domestic responsibilities because their parents have aged and they have fewer siblings living with them. Second, expectations and 'hopes for a future' are still dominant for the younger age group. Third, the size and make up of the sources of social support also differ between these two age groups of single women. When examining these three issues, it can be seen how lack of communication and social participation particularly disrupts the relationships of single participants.

Young single women: age group (a) (24-28 years)

With regards to expectations and 'hopes for a future', the younger women (aged 24-28) express their hopes for marriage and children despite its low probability. They are fully aware that under their circumstances with ESRF the likelihood of receiving a marriage proposal is rare. However, doctors have told them that there is a possibility of regaining their health if they have a successful transplant. They also base their aspirations on the case of Lena, a 27 year old security employee at the dialysis centre, who had received a successful kidney transplant. This woman became the living example of their dreams. They first met her when she was undergoing dialysis treatment with them; and then they observed her health condition improve after she had undergone a successful transplant and returned to work at the dialysis centre. When she got married, they expressed great anticipation for themselves. In expressing hope, Bayan states:

'Seeing Lena (an employee at the dialysis centre) gave me a great hope; you see she was the same age as I was when she was first diagnosed with renal failure and now Mash'Allah, [God protect you from envy] I see her back at work after the transplant. I was very happy to see her wedding photos because now I see that my dreams of marriage can also come true.' Bayan (A-S)

Since they are in their twenties, these women feel that time is still on their side and they cling to their hopes of having a successful transplant. They speak of marriage in terms of 'when I get better' or 'when things change.' But they are uneasy discussing their personal hopes with female relatives of a similar age because they fear being patronized or pitied. They become anxious and agitated when comparing themselves to their female relatives in their twenties who are settled into married life and motherhood:

'I feel sorry for myself when I compare my sisters' or cousins' life to mine, but this is my naseebi inkatab [referring to destiny] and I have to accept it.' Marwa (A-S)
'Girls at my age are all settled in their own homes. Four of my sisters are married and have their own children; my older sister’s oldest daughter has just got married last week. When I compare my life with my sisters or cousins, I realize what this illness has taken away from me and what my life could have been. Astaghfurallah [God forgive me], I just pray Allah [God] provides me with patience, so I don’t lose my mind.' Rana (A-S)

It is during feelings of hopelessness that these younger women turn to their mothers and aunts for companionship, comfort, encouragement and reassurance. It is primarily their mothers and aunts who continuously reassure and uplift them by boosting their self-esteem and encouraging them to maintain hope for their future:

'I know that my mother and aunt are a great source of comfort for me. Their words are very encouraging and they help me think that my life may change for the better one day.' Bayan (A-S)

With regards to sources of social support that provide companionship, comfort, encouragement and reassurance, the younger single women in age group (a) did not get much of an opportunity to make friends outside their family circle because they had been inflicted with ESRF at a younger age. As a result, their social circle was primarily the immediate family and close relatives and unfortunately for them, their relatives have an active social life of their own that excludes these young women because they are unable to fully participate in family activities, i.e. shopping, outings and parties due to their medical regimen and condition. Either their dialysis schedule may conflict with their relatives' social schedule or their medical condition exhausts them:

'I miss out on so many family activities because I have to go to the dialysis centre three times a week. Even so, I get tired easily and don’t really feel like going to family functions.' Marwa (A-S)

Yet these young single women also relate emotional reasons that keep them from fully participating in family activities; they feel left out. These feelings keep them from engaging in conversations about social events they do not participate in. They do not want to vicariously enjoy events that they are unable to directly enjoy themselves. So, they excuse themselves and leave the room in order to hide their unease. However, by not revealing their true feelings, they are further isolating themselves from their social support group. Thus, their lack of participation disrupts their relationships with family members of a similar age:

'So many times I don’t tell my family how I’m feeling; I just always keep it in my heart. Even when they ask me I make up an excuse and leave the room.' Bayan (A-S)

When these younger single women started attending the dialysis centre, their sources of social support expanded to include non-relatives. They were eager to accept fellow-patients, who were also young and single as 'friends' and began referring to them as such. They began to exchange personal stories with their new friends that they could later share with their sisters and cousins.
'I don't want to complain to my family, but I need to talk to somebody. So I turn to my friends (fellow-patients) at the dialysis centre. They help me a lot with their understanding and advice. We share everything about our life together, not just the illness. We see each other every other day at the dialysis centre and we talk on the phone also.' Marwa (A-S)

'Though we (fellow-patients) are on dialysis, we still talk and laugh at what happened to us or to someone in our families. I many times wait until I go to the dialysis centre the next day to hear what happened to my friend (fellow-patient) at her cousin's wedding or another occasion. Then I will have something to say when I get back home.' Rana (A-S)

This unique relationship with fellow-patients made them feel normal and more like female relatives their own age. As a result, their social life revolves around the dialysis centre.

Other single women: age group (b) (29-35 years)

In contrast, the single women aged 29-35 did not seem to share the same expectations and 'hopes for a future' with their younger counterparts (age 24-28). In fact, when questioned during the interviews about prospects of marriage, some of them brushed it off with comments such as, 'that's gone', 'that's over with', 'once upon a time, not now.' However other comments on the subject do reveal that they too hold on to their dreams of marriage and children. The only difference between these two age groups can be seen in subtle expressions. Women in age group (b) are more bashful about openly expressing their desire for a husband and children, although an inference can be made when Sulafa (B-S) jokingly comments: 'We are having guests over tonight; maybe they are khutab [proposals for wedding].'

Although, single women of both age groups have the same aspirations of marriage and children, the women in age group (b) are aware that they are no longer expected to fulfill them. The realization that they may never have their own children causes them great sadness and self-pity:

'I don't mind taking care of my sister's children. I like it, although I'm unable to handle them for long periods of time. But what makes me feel really sad is to know that I will never be able to have my own family with children of my own.' Areej (B-S)

These women openly discuss how their family members and acquaintances regarded their dreams. They were not encouraged to dwell on the possibility of marriage unlike the single women in age group (a), because in Saudi society even healthy women in their thirties do not have good prospects for marriage. Thus, family members' and acquaintances' perceptions influence how these single women in age group (b) perceive themselves.

Instead of hoping for marriage and children, they focus on how their family roles and relationships have been disrupted since the onset of ESRF. They comment on how they once considered themselves to be a family asset prior to their illness; but now see themselves as an imposition because they can no longer contribute to the
domestic support of their family. All five of them had been actively involved with their families, but now due to their medical constraints they find that their social activities have been drastically curtailed or eliminated altogether. They seek comfort, encouragement, reassurance and advice from their female relatives and fellow-patients to counter their feelings of hopelessness and desolation:

'At times when I feel all the doors are closed in front of my eyes and I feel sad and there is nothing I can do, I call my cousin or my aunt and ask them to come over because I want to talk to them; or I say that I need to show them something.' Nawara (B-S)

The older single women had more sources of social support because prior to the onset of ESRF they had the opportunity to make friends outside of their family circle. Some report that these friends remained in their life subsequent to the disease. Although all of these women express some feelings of isolation, it is not to the same extent as their younger counterparts since they have access to more sources of social support to turn to for companionship, comfort, encouragement and reassurance. It can be seen that as the sources of support decrease, the less these women communicate their fears and concerns. A distinction can be seen between those older single women who lost contact with friends after becoming ill and those who remained in contact with them after the onset of their illness. Thus, having a larger set of acquaintances to rely on for companionship and encouragement is often a source of great comfort:

'They were my neighbours for 10 years in the old apartment. I have known them for a long time; we used to do so many things together.' Arwa (B-S)

'She (referring to an ex-neighbour) is like a sister to me. Though we don't meet all the time now, we still speak on the phone almost every other day. She stays in touch with me and I do the same.' Sulafah (B-S)

The three younger women in age group (a) were found to be mainly concerned about themselves and their condition, and did not report being concerned about how their illness affected their social relationships. Instead, their relatives (mainly mothers) doted on them in order to compensate for their inability to fully participate in family functions. Sympathetic family members allowed them the freedom to openly complain. They were able to express their feelings and fears, knowing they would receive encouragement and reassurance.

On the other hand, the five older women in age group (b) lack the time to focus on themselves as they have to care for their elderly parents and any younger siblings that still reside with them. In addition, their role as aunt to their married siblings' children is an added responsibility. Family expectations influence how these participants relate to their relatives. They are expected to baby sit young nieces and nephews even though they are sick. Unlike their younger single counterparts, their complaints are not so readily accepted because they must bear family responsibility. They do not feel comfortable complaining about chores they are expected to perform. Since they are much more reticent than their younger counterparts in this regard, their lack of communication with their relatives is a cause of stress.
Despite these differences in attitude between the two age groups; all of the single women shy away from fully participating in family functions involving zawaj [marriage] plans, aquikah [baby shower] or other social commitments involving their sisters or female cousins. These women state that it is not out of apathy that they choose not to attend, but out of feelings of disappointment that they may never be the recipient of such attention. Since family life focuses on such events, these women become more isolated and lonely the more they become uninvolved.

**Ever married women with children**

The primary distinction between ever married participants and single women is motherhood. Concerns for their children are highlighted throughout their interviews despite the urgency of their health condition. This preoccupation with their children often dominates their life to the point of making their illness a secondary concern. These women focused on their children when discussing the reasons for their lack of communication about their health problems. (This issue as it relates to the marital relationship is discussed in the following section addressed on 'loss of marital intimacy'). They explained that one of the reasons for not expressing their discomforts and fears to their children, in particular, their younger children, was to protect them from the harsh reality of their disease. They did not want to depress their children and cause them further stress:

'It's bad enough that my children know that I'm sick and have to go to the dialysis centre three times a week. I can't hide that. But I don't have to tell them that I feel sad and depressed about my condition. I don't want them to worry about me, but sometimes they see my face and ask me 'what's wrong?' I always tell them that 'it's nothing; I'm just a little tired'. Afrah (B-M)

'I don't talk about my discomfort and fears with my family, especially my younger children. My divorce is already a source of problems for them, because we no longer live together in our own home. I'm now living in my Uncle's house with my three daughters and my two sons live with their father. My daughters are already very busy helping me with household chores, and I don't want to complain to my sons when they visit me. I can't help but blame my condition for my divorce and the separation of my children. I always feel weighed down, because I can't share my feelings with them.' Rehab (D-D)

Another reason for not sharing their problems with their children, in particular, their married children, is their fear of over-burdening them because they have their own families to care for. This is demonstrated when these women refuse to accept their married daughters' assistance with household tasks. Even though they have their own family, these daughters always try to make themselves available to their mothers. Yet when they do volunteer to help, they express their worry about leaving their own children at home or having their husbands transport them. So these participants fear that they are taking their married daughters away from their own families, which may cause some family discord. Thus, they push themselves harder than they should to try to maintain a façade that they are still capable of managing their own domestic responsibilities. Although their intentions are noble, the result is detrimental to their relationships as well as their condition. Their married daughters are under the false impression that their mothers can handle everything and so they are free to attend to their own life without having to
consider their mother's illness. These participants then feel that they have been ignored and they begin to harbour feelings of resentment which places a wedge between themselves and their married daughters.

Yet it is ironic when this same group of women complained that their children do not make inquiries about their state of health, which they interpreted as a lack of concern for them. Their effort to protect their children from worrying about them by not disclosing their apprehension to them, in effect, silences these women and eventually leads to their isolation and emotional distress:

'I never wanted to take my married daughters away from their family to come and help me in my home. I didn't think it was fair. Since I have gotten weaker and older I now need their help; but they are used to me not asking for it, and sometimes I feel neglected.' Sonia (D-W)

All ever married participants with younger children admitted to never openly discussing their feelings with their children. It was surprising to discover that this lack of communication was also characteristic for those participants who had ESRF for many years:

'I don't care how long I've been ill; I don't want to show how tired I feel. When my children come into my room, I always try to sit up and put a smile on my face. I use all the energy I have to ask them questions about their day, so as to prevent them from asking me questions about my day at the dialysis centre.' Abeer (B-M)

It is important to note that these women who are generally reticent when it comes to communicating with their husband and male relatives become assertive in matters involving their children. The primary concern for the 40 mothers who have children living with them is the welfare of their children. Instead of dwelling on themselves, they are preoccupied with how their illness affects their children's future; especially after their death. Their immediate goal is to strengthen their relationships with their husband and male relatives who will be ultimately responsible for the care of their children after their death. They make an effort to spend much of their time discussing their children's needs with their family members.

Even though their family reminds them that their illness may not result in a shortened life, they still seek reassurance from them regarding their children's future. They remind their husbands and male relatives that when the time comes (their death), they must share the responsibilities for their children. For the first time, these women comment that their husbands show more sympathy by listening patiently and responding to their concerns. I detected relief in their voices when they reported how their husband and in-laws reassured them that they will meet all of their obligations towards the children. Such reassurances grant these women some peace of mind:
'Though I'm a true believer, and I know Allah [God] will bestow his mercy upon my children, just for my mind to rest, so I can manage to survive the challenges of this illness, I take my family member's words (family's promise) that when I die they (her young children) will be cared for.' Waseela (C-M)

'I may not get much sympathy from my husband when it comes to my illness, but he does give me relief about taking care of my children if anything happens to me. His promises about this make me sleep a little better at night.' Abeer (B-M)

Their medical regimen is another reason why these women experience a disruption in their family roles and relationships. Depending on the dialysis shift, they may miss seeing their family leave to go to work and school in the mornings or they may miss them as they return home in the afternoons. Either way, they feel that they are missing out on their family's highlights of the day. When they return home from dialysis, they are usually too tired to catch up on family affairs:

'When I'm on the morning (dialysis) shift, I don't get to see my children off to school and I'm not there when they get home. I also miss out on the lunch when they talk about their day. So, I don't get to hear their news about what happened to them. I feel sad because I know I'm missing a lot.' Waseela (C-M)

The data suggest that ever married participants end up internalizing their worries over their health, rather than openly discussing these concerns with their family. They are sensitive to how their illness has drained the family of its time and energy. With all of the practical and financial support they require from their family, they do not want to overburden them with their complaints and worries. They choose to keep their problems to themselves for fear of upsetting them.

As with their single counterpart, the realities of ESRF also prevent ever married women from fully participating in family activities. A substantial amount of time is spent away from their homes when they have to attend to their dialysis therapy. During these long hours, they are usually alone while their families are busy with their social life, so they cannot help but feel lonely. Despite their exhaustion and discomfort associated with chronic renal failure, all of these women try to participate in family activities. The major activity for these women is meal preparation. For every family social event, there is a gathering of womenfolk who get together to prepare the dishes. At times, their relatives do not invite them to engage in this family tradition because they are mindful of their dietary restrictions and try to avoid tempting them to eat forbidden foods:

'I know that at times when I'm really exhausted, I try to get out of going to these family gatherings by reminding them of my dietary restrictions. So, I know that they are only trying to help me when they don't invite me. But I still feel like I'm being left out.' Afrah (B-M)

Even though their relatives mean to be considerate, not inviting them actually disrupts these women's relationships because they are unable to fully enjoy their relatives' company. Since this is an opportunity for these women to socialize and catch up on family news, their lack of social participation increases their sense of social isolation.
Loss of marital intimacy

The side-effects of ESRF, e.g., physical exhaustion, interfere with the intimate aspects of marriage. They result in the loss of intimacy between husband and wife which ultimately disrupts the marital relationship.

Married and separated women

All married and separated women reveal how ESRF disrupts their marital relationship and their role as a wife, resulting in intimacy problems. This is a particularly sensitive issue since both Saudi society and the Islamic religion regard the marital relationship to be absolutely sacred and paramount to all others. Even in the face of modern trends, Saudi society expects that no obstacles should be permitted to interfere with this relationship. However, this culturally 'revered' relationship sometimes has to take a back seat to the demands and limitations of these women's medical regimen. Thus, all marital activities must be scheduled to 'fit in' with the dialysis sessions which prove to be inconvenient. When they get home, either their husbands are unavailable or unreceptive to marital relations; or the participants are too exhausted and disinterested in sex. But it is the lack of companionship that they reported to mostly miss. Their disease not only physically dissipates them; it also forms a barrier between them and their husband that disrupts the marital relationship:

'I think my husband is afraid I may start talking about how badly I feel because he never asks me how I feel. He no longer comes in to sit with me or joins me to watch television. As soon as he comes home, he involves himself with the children or gets busy doing little things. He never spends any time with me, except when he takes me to the dialysis centre. I feel I'm just another responsibility for him.' Rabha (C-M)

All married women reported that the loss of intimacy is the result of the participants' lack of communication with their husband. They believed that this is a reason for their estrangement and complained that they had difficulty expressing their emotions about their discomfort and fears. They state that the reasons why they did not voice their true feelings is that they wanted to avoid angering their husband and losing whatever intimacy they did share. Although their concerns are valid because they have previously experienced their husband's negative responses when relating their concerns to him, ironically it is also this conscious effort not to annoy him that contributes to their loss of intimacy:

'He (referring to her husband) doesn't ask me, so I don't tell him. If he doesn't want to know how I feel, I won't say anything. I'm afraid he'll get angry with me and go out. He's done that before. It's upsetting and I don't want that happening again, so I just keep quiet. I'd rather have him in the house, at least.' Sabra (C-M)

Interestingly, these women excuse their husband's abrupt attitude, because they are aware that he is under a great deal of stress due to financial burdens and non-domestic obligations, i.e., transportation, shopping, etc.
'I know my husband has a lot of responsibilities; that's why he is short-tempered. He has money problems and is always complaining about the costs of transportation to and from the dialysis centre.' Hasna (C-M)

Also, they point out that one of the reasons for their husbands' abruptness may be due to the prevalent belief amongst Muslims that one does not complain about personal problems to others, but should instead refer themselves to God. On the other hand, they are under the impression that their husband may use this merely as an excuse to avoid uncomfortable issues:

'I wanted to tell my husband about my deteriorating condition, but he would always cut me off by telling me to have faith in Allah [God] and not to think of the future. His manner was like a warning for me. He didn't want to hear it, so I stopped trying to talk to him about what really bothers me. His attitude makes me very sad and lonely.' Abla (D-M)

Seven women who are separated from their husband (but still legally married) found themselves in the 'embarrassing' situation where they were actually deserted by their husband. These women explain their husbands' absence as an extreme response to burdens that they can no longer cope with. In these cases, the women no longer have a life that resembles a 'real' marriage since there are no conjugal visits and little if any communication whatsoever; however, they may receive some financial assistance and the 'appearance' of being married. As long as there is no divorce, the appearance of being married will last forever (love is not the issue here). This appearance of marriage is just as crucial to these women as the reality of marriage itself, since they lack the financial resources to support themselves. Although their marital relationship has been completely disrupted because it no longer exists, the status of being married enables them to hold on to the title of 'wife' and the hope that as long as she has this title, reconciliation may take place:

'My husband and I are still married, but we are not living together. I hope after my transplant, we could get back together.' Sahar (A-MS)

Even though five out of seven of the separated women had to move out of their 'marital' home to live with a male guardian, all of them kept their children. For the two women who remained in their home, there was an expression of relief. Fatoo, who remains in her own home with an older son states:

'Although my husband is no longer living with me, I'm still married and no one can claim otherwise. People still see me as a married woman so I am given the same respect I had when he was living with me. My children remain with me and we can stay in our home. That's important. Being divorced is looked at as a failure and the fault is always with the woman.' Fatoo (D-MS)

The husbands of five out of the 12 divorced and separated entered into polygamous relationships after their wives became inflicted with ESRF. Eight out of the married women stayed married to their husband and live in a separate home from the second wife. The remaining woman is separated from her husband and had to move in with their legal guardian. According to the Islamic Sharia'a [law], husbands involved in polygamous relationships are supposed to share their time
and money equally between their wives. In reality, in all of these cases, the participant's husband spends most of his time with the second wife and only visits the participant to check up on the children or run a quick errand:

'My husband always chooses the days I have dialysis to be with me. But he's only with me when he drives me back and forth from the dialysis centre. I don't really get the time to be with him. He doesn't stay at the dialysis centre with me. He goes off. He's probably with his other wife or doing errands for her. Anyway, he's not there for me. I don't get any personal time with him at all. By the time he gets me home, I'm too tired and I end up going to bed. He's either watching television or on the phone.' Fatin (A-M)

Women in Saudi society are always mindful of the possibility that their husbands may marry another wife, since polygamy is permitted in Muslim societies. Although many husbands refrain from this choice, it becomes a more realistic concern for the chronically ill woman since it is culturally acceptable for a husband to take another wife when his first one becomes ill and cannot perform her conjugal duties. Thus, this loss of intimacy makes chronically ill women feel like strangers to their own husband.

**Divorced and widowed women**

Divorced and widowed women are different from their married and separated counterparts because they no longer have a husband for companionship, comfort, encouragement and reassurance. However, there is a difference between the divorced and widowed women with respect to in-laws. The divorced women's in-laws seem to only maintain relationships with her children since they usually blame them for the divorce; whereas, the in-laws have sympathy for the widowed women and therefore still maintain their relationships with them. Even though married participants lack communication with their husband, they still obtain a sense of security from the fact that he is occasionally available at home and is still the authority figure for the children. Although the separated participants no longer live with their husband, they still maintain a glimmer of hope that he will take them back.

Eleven of the 14 divorced and widowed women had to move out of their home to live with a male guardian after divorce or death of their husband (Table 8.1). This further decreased their sources of social support since the relationships they had formed with in-laws and neighbours over the years were suddenly removed from their daily life:

'What I ended up missing most when I had to move-out of my home was the relationships I had with my jeran [neighbours]. I knew them for many years and then suddenly I didn't see them anymore. Now I have only my family to depend on.' Maisa (D-W)

'Very in-laws were upset when I got divorced, even though it was my husband who divorced me. Somehow it was my fault. My children and I had to move in with my brother. I never see them (her in-laws) now.' Hayat (C-D)
When the dynamics of marital relationships for Saudi women with ESRF change as a result of polygamy or desertion; or when their marital status changes due to divorce or death, their role as wife is severely disrupted. As a result of the loss of marital intimacy, all of these women become more emotionally vulnerable which further jeopardizes their health.

**Loss of domestic authority**

In Saudi society, the woman's domain is her home which includes everything and everyone who is a part of it. It is only within this sphere of influence that the male authority is subordinate to hers, for men are raised to believe that women know best in this particular area. Thus, domestic authority (managing household chores and childcare; performing personal care) rests solely with female members of the family whose importance and status is directly linked to family care-giving roles. It is when disability inhibits them from physically exerting themselves or closely monitoring surrogate care-givers that they sense an erosion of their domestic authority. Over time, these women find themselves in a subordinate position within their own home. This lack of domestic authority translates to a loss of her care-giving roles and relationships. Yet, instead of surrendering these roles to family members, they struggle to maintain them because they understand that these roles are the only means to maintaining their status.

Marital status and motherhood affect the issues arising out of the loss of domestic authority. As previously stated, single women are not the primary caregivers over their family; thereby loss of domestic authority does not sabotage their family relationships.

All ever married women in this study who live in their own home (i.e. not with a guardian) try to maintain their control over domestic affairs by emphasizing that everyone in the household continue to defer to them before making decisions. Unfortunately, their perception that they are maintaining control over the household is an illusion, because they are not always available due to their frequent visits to the dialysis centre. For all practical purposes, they reluctantly have to relinquish their authority to a daughter, sister or another female relative:

'I don't want anybody to run my home. That's my responsibility and that's the way it should stay. But I realize that I'm no longer at home as much and someone has to take care of the chores and the younger children. It still bothers me though.' Basma (B-M)

Twenty-five ever married women depend on their daughters aged 13 years or over (Table 9.1) who still reside within the home to perform the duties they are no longer capable of doing properly. Amongst these 25 women, role-reversal was the dominant issue raised throughout their narratives since it is a critical factor leading to the loss of domestic authority that these women were once accorded in their homes prior to the onset of their illness. They no longer see themselves as the integral player but merely as the figurehead, who may still issue orders but is unable to follow them through. Their children may disregard their orders by replacing them with their own choices; and the fathers address their concerns to
their older daughters to avoid lengthy discussion with the mothers. These women see their family care-giving roles changing as their children take over:

'I know I need my daughters to help me with chores and babysitting when I'm at the dialysis centre. I must leave the decision making to them because I'm out of the house for at least 6 to 8 hours during this time. It seems that I'm not the mother anymore, my daughters are and when I get home it's difficult for them to ask me permission before they do any chore. When I give them instructions they ignore them, and do what they think is right. I can understand this, but I'm still the mother and I feel I must maintain this role or else who am I?' Badia (C-M)

It was especially difficult for married women who complained that their husband referred to the children when inquiring about their condition rather than asking them directly. They overheard their children describing their mother's activities to satisfy their father's inquiries, after which he would either watch television or leave the house. Eventually these women felt left out and more isolated within their own homes:

'I'm still the mother; my husband shouldn't ask my children questions about me. He should ask me directly. It bothers me that he no longer sees me as the person in charge in my own home.' Sumaya (D-M)

Although all 25 women with daughters 13 years or more understood they needed their children's assistance and that it was the only way they could maintain some semblance of normality within the home, they were still ashamed that they were no longer able to fulfil their domestic role obligations due to physical and medical limitations. The mothers expressed feelings of guilt when describing how their children had assumed their domestic responsibilities:

'No matter how much I tell myself that it's not my fault that my children have to take on a lot of the responsibilities around the house, I feel guilty. I was raised believing that this is the most important job a woman can have; taking care of a husband and children. Now I can't do it the way I should.' Rogaiah (D-M)

Even though these women preferred to maintain their home themselves, they were thankful for their daughter's efforts and considered them to be blessings from God. Nevertheless, they often felt conflict because of the ever-growing burden placed on their children:

'I feel confused about making children work so much. Yet, I must thank Allah [God] for them because they are true blessings. After all, without my children my home would never be normal. But I can't help myself feeling guilty about putting so much on their shoulders.' Sultana (D-W)

Ten of the ever married women either have only daughters less than 12 years old or only sons who within Saudi society are not be delegated domestic responsibilities. Since these 10 women must depend upon their female relatives who live outside their home for domestic support, they perceive their growing dependency as a threat to their domestic authority, as well as to their status within the family. Mana, who doesn't have older daughters to depend on, states:
'I have to call my married sister or cousin to come to my house and help me. It is very difficult for them to manage helping me when they have their own families. I feel that they are replacing me in my own home; but sometimes I need them.' Mana (B-M)

There is a different reason for the loss of domestic authority amongst the 16 out of 21 women who were previously married and do not live in their own home (Table 8.1). As was stated in Chapter 8, these women were forced to move out of their homes and into that of a male guardian. Once they and their children move into a guardian's home, they had to learn to obey the rules of their extended family. Since these mothers had to defer to the authority of their host extended family, they were no longer the primary authority figure over their children. They and their children were constantly being scrutinized by their extended family which caused them anxiety:

'Since I've had to take my children and move into my uncle's house, I am always nervous. My uncle's wife is always telling my children what to do. Sometimes I disagree with her, but I don't feel I have a choice. Now they go directly to her to ask permission for everything.' Rehab (D-D)

A consequence of relinquishing their family care-giving roles for all of these women is the burden of feeling guilty. At times it is apparent that these guilty feelings and anger come to the fore, especially when they struggle to maintain control by asserting themselves or resisting help from their family and friends. The inability to perform their duties and the acknowledgement of having to accept others' assistance results in additional negative feelings of diminished self-worth and self-pity.

**Loss of privacy**

The loss of privacy is not an issue amongst the eight single and the 21 married women who live in their own homes. However, it became a major issue for the 16 women who were forced to move out of their home and into that of their guardian due to separation, divorce or death of the husband (Table 8.1); and therefore no longer have a mahram [male related to the female by sanguinity or blood relationship] living with them:

'I no longer have a place of my own. I share space with everyone who lives in the house. I have no escape when I am tired and upset. I have to sit with my relatives and pretend I'm alright. It's so tiresome.' Maisa (D-W)

These women now live under strained conditions since they no longer have a home of their own and their private space has been reduced from an apartment or house to a single bedroom. They are also required to share the rest of the family quarters with all host family members. Although they are living with a male guardian (father, brother, son, or uncle), their status in the family has been relegated to that of a daughter, sister, mother or niece; and within this changed status, the previously married women, no longer has the authority to make any decisions for herself or her children and no longer has any domestic authority in
their guardian's home. Since their extended family with whom they reside must bare the burden of providing financial and domestic support, these women have lost their sense of having any control over their life.

**Conclusion**

This chapter finds that the debilitating effects of ESRF on the physical and mental health of Saudi women have greatly disrupted their family care-giving roles, interpersonal relationships and emotional well-being. This chronic disease does not only cause personal discomfort and inconvenience for its sufferer, but also impacts negatively on the entire family network that is the primary source for the patient's social support. Failure to fulfil most of their family obligations leads to feelings of guilt and shame. As these negative feelings increase, the less these women communicate with their family and the more they withdraw themselves from social gatherings. These women become more isolated from their family which leads to the deterioration of their inter-personal relationships.

More importantly, when ESRF impedes communication between these women and their husband, they lose the intimacy that is crucial to maintaining a successful marital relationship. Erosion of family companionship leads to the eventual loss of comfort, encouragement and reassurance for these women. Saudi women suffering from ESRF also lose their domestic authority which diminishes their identity as the primary caregiver for their family. In addition, the loss of privacy becomes very problematic to those previously married women who must leave their own homes and move in with their guardian and his family. They no longer have a home of their own, nor do they have a say over their personal concerns that affects them and their children. All of these 'losses' along with increased dependence on relatives for family support inevitably add up to the loss of control over aspects of life that define who they are within the family and society.
Chapter Eleven
Saudi Women's Responses to Managing Life with ESRF

The main purpose of this chapter is to examine how Saudi women with ESRF respond to their competing demands in order to manage their illness and their new way of life. This chapter further explores the success or failure of particular actions taken by these Saudi women in managing various aspects of their life. Since it can be seen that their life is divided into four main aspects: religion, health, financial and social aspects; actions are analysed in light of each of these aspects. Nine specific actions are explored, each of which is used by the participants in this study. These actions are denial and/or minimization of symptoms, acknowledgement of physical limitations and integration, forming new relationships with fellow patients, trial and error, dependence on others, withholding thoughts and feelings, participation and withdrawal from family social activities, resignation and accommodation, and prayer. These actions are further assessed in terms of how effective they are in attaining these women's desired goal of maintaining normality.

Like all chronic illnesses, end-stage renal failure has irreversibly transformed the way of life of these Saudi participants. The women suffering from this illness not only experience severe health problems, but also experience dramatic changes in the social aspects of their life. All of these changes that arise out of their medical condition ultimately result in a metamorphosis of social aspects of their life as well.

Initially, all participants defined normality in their life as having the ability to maintain their family-related roles and relationships and fulfil their family and marital responsibilities. But they learned to modify this definition when they recognized that the nature of their physical limitations caused by ESRF impedes their efforts to continue their original way of life. They no longer viewed being normal in terms of what they 'used to be able to do' when they were healthy, but rather in terms of what they 'can do now'. Thus, their altered way of life seemed to redefine their understanding of normality.

The research showed that for all participants' their life had become more stressful when they were unable to manage the competing demands that stemmed from their daily tasks and responsibilities. Their failure to manage these competing demands also impeded them from achieving their long-term goal of maintaining normality. In order for them to maintain normality in their life, they have to resort to various activities to manage their everyday life.

Denial and/or minimization of symptoms

All of the participants reported that they had hoped that by ignoring and refusing to talk about their condition, the symptoms would soon disappear. Denial and/or minimization were used by all participants to emotionally insulate themselves from the initial shock they felt upon hearing the diagnosis. They state how they initially discarded the long-term aspects of ESRF by not properly following the recommended diet or not resting sufficiently; and attempting to conceal their condition from family and acquaintances by resuming their responsibilities as soon
as they 'felt better'. As described by Basma when she was first diagnosed with chronic renal failure:

"The doctor told my husband that it was a 'renal attack', but I refused to believe that at first, because I thought it was just some back pain that would go away by the medications prescribed to me. I even stopped taking those medications three or four days after my visit. I felt better; I ate whatever I wanted, no more nausea or that heavy feeling on my back. I went back to my usual (domestic) work and tried to forget about it (the renal attack). Even when my husband or anyone else asked 'how are you feeling now?' I used to say Alhamdullilah, [thank God] I'm fine'. For a long time after that I continued to refer to that attack as a back pain, never referred to it as a renal attack, as the doctors referred to it. I thought if I ignore it (pain) or didn't talk about it; it was going to go away.' Basma (B-M)

All participants employed denial and minimization to assist in their goal to maintain normality. It can be seen that age and marital status influenced how this action was utilized to manage different aspects of their life. A distinct difference can be seen regarding the perception of normality based on marital status: single women in age group (a) (24-28 years) tried to deny changes in their physical appearance in order to hold onto their hopes and dreams of getting married and having a family; while single women in age group (b) (29-35 years), and all ever married women denied their physical limitations in order to try to maintain their care-giving roles and relationships (see Chapter 10).

Denial of changes in physical appearance

The three young single women also used denial and/or minimization to assist them in managing their emotional well-being by minimizing the changes in their physical appearance. Because of their young age, they desired to preserve a healthy and attractive body-image so that they could maintain their hopes for marriage and motherhood. They denied the reality of their illness, despite their knowledge that over the years none of the fellow-patients in their age group ever got married. Bayan expressed:

'One day I hope to get married and have my own children, it would be a dream come true.' Bayan (A-S)

Similar to the young single women, 21 married women (excluding the seven who are separated from their husbands) still needed to manage their emotional well-being in order to maintain their hopes of remaining married. The difference between these two groups is that the hopes of the married women focused on maintaining an intimate relationship with their husband. By applying cosmetics and wearing long-sleeved garments, they were hoping their husband would not notice the changes in their physical appearance and still find them attractive.

Denial of physical limitations by undertaking 'normal' domestic responsibility

All 28 married and separated women along with the five single women in age group (b) and the 14 divorced and widowed women also used denial and/or minimization to attempt to manage the social aspects of their life. The practical
demands of the older single women (aged 29-35) are similar to those of the married, divorced and widowed women because even though they are unmarried, they also bear domestic responsibilities (see Chapter 9). Furthermore, all of these women focus on trying to maintain their family care-giving roles and relationships (see Chapter 10).

By denying and minimizing their physical limitations, they attempted to perform all of their household tasks and social obligations and were reticent to ask for help from family members and acquaintances. However, all of these participants admitted that denying or minimizing their condition exacerbated their ill-health:

'I didn't want my family to think I couldn't manage my own home, so in the beginning, I refused to ask for help and tried as hard as I could to do everything myself. I thought that if I didn't do all household work by myself, my husband and children would think I wasn't a good wife and mother.' Afrah (B-M)

Comfort and well-being of their families depends on these women's ability to manage practical tasks, which in turn allows them to maintain a perception that they are fulfilling their family care-giving roles and relationships. Thus, normality is defined by maintaining social aspects of their life. However, inner struggle arises when their desire to maintain inter-personal relationships is in conflict with their ability to fulfil practical tasks.

Denial of medical complications

The 23 women between the ages of 24-39 years used denial and/or minimization to assist them in managing their emotional well-being. By denying and minimizing their additional medical complications (i.e., high-blood pressure, diabetes) that make them a high-risk recipient, they were able to maintain their hopes for a successful transplant. This action was self-deceptive because they knew that eventually most of their fellow-patients' transplants failed returning them to dialysis therapy. Yet, they continued to hold on to the belief that they would get a transplant which would be successful because they were younger than these other patients. They denied the fact that these older women had received their transplants at a younger age like themselves and continued to minimize their health condition in order to compare themselves to the nurse (Lena) who had undergone a successful transplant:

'I see Lena (employee at JKC) every time I come to the dialysis centre. She's doing well with her transplant Alhamdullilah [thank God], and she's my age. Seeing her gives me hope.' Fatin (A-M)

Denial and minimization of the illness serves an important emotional management function at the onset of diagnosis by giving all the participants time to emotionally adjust to their illness. However, if continued over a lengthy period of time, this same action would prove to be life-threatening because of the adverse effects it would have on their health management, such as, ignoring dietary restrictions and overworking themselves. Once they acknowledged their condition and the consequences of denying it, they replaced this action with a more beneficial one that enabled them to successfully manage their practical tasks and emotionally manage their inter-personal relationships.
Acknowledgement of physical limitations and integration

All participants use acknowledgement and integration for health management when attempting to take an active role in managing their illness. Activities that characterize acknowledgement regarding the health aspects are identified as: recognizing the conditions of the disease, seeking information about their condition, and actively engaging in the medical regimen. Once the participants acknowledge their condition, they attempt to integrate their medical regimen into their daily life by: monitoring fluid intake, maintaining a proper diet, consistently weighing themselves and following the dialysis schedule three times a week. By integrating their medical regimen into their life, all participants report they were able to overcome their fear of both the dialysis machine and the therapy itself. Thus, these activities aid them in managing their emotional well-being, as well as their health.

With regards to managing social aspects of their life by acknowledging their physical limitations, participants' age and marital status must be considered.

Young single women in age group (a)

The young single women (age 24-28 years) are different from the other participants because they did not have to drastically modify the social aspects of their life to adapt to their health limitations. Since they were assigned to do very little of the domestic chores prior to the onset of their illness, subsequent physical limitations did not affect this aspect of their life. They only needed to manage their illness and integrate the medical regimen into their way of life. On the other hand, their inter-personal relationships grew as a result of their illness. As Rana states regarding expanding her world beyond family:

'I personally didn't have any asdika [friends] like my sisters or cousins have, but the dialysis centre provided many of us (renal patients) the opportunity to get to know more people. You know many of us (patients) have known each other since our first visit to the dialysis centre. Some may have been there a little longer; some may be a little less. But we have now become asdika [friends]: we wait for each other and share in conversation. We have become friends who can pass the time with one another at the dialysis centre or even call one another at home.' Rana (A-S)

When the illness began, the social circle of the young single women had not widened beyond the realm of their family, because they were still living a sheltered life at home. But their visits to the dialysis centre had provided them with the opportunity to make new friends with their fellow-patients; thus, expanding their world beyond their family.

All other women

Apart from young single women, as their health deteriorated, all other women had to acknowledge their physical limitations in order to manage social aspects of their life:
'Well, as I said before we (renal patients) have to live with this illness, which means we have to understand what we can and cannot do or have anymore, or otherwise we will never be able to have any stability in our life. We will just trouble our minds and our family with our discomfort.' Hasina (C-D)

These participants admitted that since they were unable to meet both their domestic and social demands, they found it necessary to acknowledge their physical limitations and ask their family members and acquaintances to help relieve them of certain duties and responsibilities. They became more dependent on their relations as they sought their assistance in practical matters concerning transportation, babysitting and household chores (see Chapters 8 and 9):

'Believe it or not at first, I never worried about the symptoms (back pain, headaches) I used to get so I used to do everything at home myself, especially my house chores. But now it's too difficult for me and I have to always ask my family for help.' Sumaya (D-M)

Abeer, a married woman with children, states that:

'After I realized how sick I was, I stopped trying to do all my housework by myself and started doing little things at a time. But now I can only do one thing at a time and have to call my sister or cousins to come over and do the rest.' Abeer (B-M)

It is very interesting to observe that once physical limitations were acknowledged by all participants, their perceptions were also altered. Prior to acknowledging their limitations, social aspects of their life were perceived to be unmanageable. It was only after they acknowledged their condition and limitations and sought assistance, that they were able to reconcile their condition with managing their domestic and social demands.

Forming new relationships with fellow patients

Forming new relationships with fellow patients assisted all participants in managing their emotional well-being. Their reality, regardless of age and marital status, is shaped by the conditions associated with their disease. They experience their families growing weary of listening to their complaints and concerns when they discuss the effects of their treatment. Marwa, complained:

'How could ahli [my family] be so insensitive? Don't they realize I'm sick?' Marwa (A-S)

Feelings of displacement and detachment occurred when all of these women claimed that they no longer felt they live in the same world as their healthy relatives. These feelings had an impact on their emotional well-being. Thus, all of them felt the need to seek empathy from others outside their family circle. They turned to fellow-patients who had a true understanding of their condition based on having similar experiences because not only did they need to be understood, they also required affirmation of their experience with ESRF.
Initially, the association with their fellow-patients was only made during their dialysis sessions where open curtained cubicles encouraged them to engage in friendly banter to pass the time while undergoing dialysis. It was later into their treatment that they began to realize that their discussions were an avenue for freely venting their emotions and discussing personal matters without feeling shame and embarrassment. Since these were the only people who could empathize with their fears and hopes, they no longer had to resort to the same pretences that they reserved for their families:

'Having each other (fellow-patients) to share what is happening without worrying about how our feelings or fears may be interpreted, and without any of us feeling bored or uninterested in what we experience, makes our relationships with each other very important. Many times we have been there for each other; rather than disclosing feelings to our husbands or children, we share it with each other. We are each others' advisors since some of us have been through similar situations with our families.' Mana (B-M)

All participants found that they gained courage and strength to continue to cope with daily obstacles and setbacks by sharing each other's concerns and engaging in mutual acts of encouragement. They relayed how their feelings of anxiety and hopelessness were diminished when they realized that they were not the 'only one' who had 'these feelings'. In addition, forming new relationships amongst their fellow-patients expanded their world beyond the home. They were introduced to other patients' personal life, which by comparison allowed them to gain insight into their own. They also became friends outside of the dialysis centre and occasionally visited each other in their homes; others called each other on the phone for light conversation. Their closeness also allowed some of them to extend their friendship and support to other members of their respective families. This type of friendship outside of their close-knit family circle made their life more diverse and worthwhile; and they commented how they felt better about themselves. For the first time, they felt that they could contribute to family conversation now that they had stories to share with their relatives:

'I never had anything to share with my female relatives when they came to visit. I would just sit there and listen to them talk; I didn't want to talk only about my condition. I know they didn't want to hear about it either. But when I made asdika [friends] with the women at the dialysis centre, I always had something interesting to say when my akaribi [extended family] came over.' Badia (C-M)

Not only did all these women provide each other with companionship, comfort, encouragement and reassurance, they also provided each other with practical support when possible by making travelling to the dialysis centre more convenient. Those who lived in close proximity to each other tried to coordinate their transportation service.

The difference in emotional well-being was discernable between those women who developed relationships with fellow-patients and the three women who did not. These three women regularly sat alone, watched television or napped during their treatment, rather than forming new relationships with fellow-patients. Their reports of discomfort and anxiety seemed to be greater and they anticipated the
worst outcome when compared to women who shared their experiences with fellow-patients.

Forming new relationships with fellow-patients was observed to be beneficial for all participants' emotional well-being. They had attributed much of their depression and emotional stress to their families' lack of understanding and to their attempts at hiding their true feelings under a façade of normality. All of them noticed how they found emotional relief once they made new relationships with their fellow-patients.

Trial and error

Once all participants, regardless of age and marital status, acknowledged their condition and limitations, attempts to manage their competing practical and health demands went through a process of failures and successes. At first, they attempted to perform tasks that required more energy and strength than they actually had which resulted in aches and exhaustion. Then they realized that they could not force themselves to complete these tasks, so they learned to stop and rest to restore their energy before resuming domestic work. It was through an empirical process that they learned that each task required a certain amount of energy, accompanied by a certain amount of rest. Through trial and error, the participants found their 'comfort zone' that enabled them to function efficiently and maximize their strength:

'It took a while before I knew just how much work I could manage to do on my own. Sometimes I would start the day thinking I could do a lot. I would begin washing clothes by hand, soaking all of them in the sink. When I realized that I couldn't stand by the sink for a long time because my legs hurt, I put the clothes in a wash bucket and tried doing it while sitting. But soon my knees bothered me and I had to stop altogether. So, I put the washing off until the next day. The next time I had to wash clothes, I only chose a few pieces rather than trying to do the whole load at one time.' Hasna (C-M)

Through the process of trial and error, all participants learned how to reduce their symptoms. By taking fellow-patients' advice, they tried various methods to relieve their discomfort. Following the advice of fellow-patients, Ghada (A-MS) found relief by sucking on ice to relieve her thirst, and not consume excess amount of fluids.

The process of trial and error enabled all participants to try different ways and discard useless ones when managing their social and health aspects. By allowing them a certain degree of freedom of choice, they regain a modicum of control over their life.

Dependence on others

Dependence on others for assistance is important for all participants. For the single participants, dependence on family members has always been a way of life since they were living at home and were never a primary family care-giver.
On the other hand, the nine (out of 12) separated and divorced participants who had to move in with their guardians after the onset of their illness were forced to depend on their relatives to manage the problems arising out of their condition which affected the social aspects of their life. Even though their dependence came as a result of their change in marital status, it was their illness that was the actual impetus for their husbands leaving them (Table 8.1).

In contrast, seven (out of 9) widowed participants had to depend upon their relatives as a direct result following their change in marital status rather than from their illness. It was only following the death of their spouse that they were required to move in with a guardian (Table 8.1).

Since five (out of the 21) previously married women and 21 married women remained in their own homes after the onset of their illness, they had to depend on their older children or upon relatives who lived outside their home. Despite the logistical difficulties they continue to experience when making arrangements with their relatives for practical assistance, these women have to depend on their relatives who reside outside their home (Table 8.1).

Dependence can be positive for practical management when it enables ever married participants to accomplish their daily household tasks and integrate their medical regimen into their everyday life. Relying on their relatives and acquaintances for assistance can give these women some peace of mind. On the other hand, dependence can prove to be difficult when trying to manage their inter-personal relationships. These participants related that once they asked for assistance regarding mundane tasks, their relatives assumed they needed their 'expertise' on matters that were a matter of personal choice and they felt that this unsolicited advice interfered with their decision-making roles:

'I appreciate any help my relatives can give me regarding money, living arrangements and transportation; but I don't like them telling me what to do and how to do it. I may be unwell, but I'm still an adult. I don't need advice on how to take care of my own children.' Hayat (C-D)

While dependence on relatives for practical assistance lightens their workload and allows ever married women to rest properly; it can also cause strained relationships with extended family members resulting in emotional stress. Thus, it can be seen how one action used to manage practical responsibilities can have a counter effect on other aspects of their life.

Restructuring relationships

All participants, regardless of age and marital status, reveal that managing the social aspects of their life has proven to be more difficult for them than managing the health aspects of their life. They claim that it is due to the very personal nature of these family relationships that causes them to experience a higher level of anxiety and emotional distress.

When ESRF has taken a physical toll on the participants, whereby they can no longer capably manage their domestic and childcare responsibilities, their
continued reliance and dependence on relatives and acquaintances leads to restructuring the terms of these existing relationships.

Restructuring existing relationships was a way of assisting participants in managing the everyday aspects of their life. As long as a balance existed between them, role reversal was helpful in maintaining normality within the home for all participants who have daughters (over age 13) living with them. When restructuring existing relationships, the participants necessarily relinquish some of their authority so that their daughters can perform domestic tasks and help fulfill their mother's responsibilities. However, the downside of this restructured relationship occurs when the participants' authority was totally replaced by their daughters'.

**Role reversal**

Role-reversal is a prime example of restructuring an existing relationship. This can be seen with all ever married participants who had to rely heavily on their daughters who live in the same household. As a result, role-reversal became a way of managing domestic tasks. This shift in domestic responsibilities from the mother to daughter became necessary in order for the family to maintain their daily routine. Thus, the daughter was required to cook, clean, iron and baby-sit so that a semblance of family normality was preserved. It important to realize that role-reversal did not only occur with daughters 13 years and over. Women who only had daughters 12 years and under had to depend on them until a female relative living outside her home was available.

However, when mothers had to overly depend upon their daughters to perform their domestic responsibilities, it became very difficult for their mothers to assert parental authority over their children:

'Alhamdulilah, [thank God] my daughters help me with everything, so I shouldn't complain. But sometimes, they can go too far, especially when they go ahead and do things, like letting the younger children stay up late on a school day. When I tell them they must make sure that my bedtime rules are followed, they remind me that it's not easy to get them to bed, and that I'm not always around to see what's going on, because I'm at the dialysis centre.'

Waseela (C-M)

Under these circumstances role-reversal was not helpful; instead, it actually undermined them. It resulted in jeopardizing inter-personal relationships and disrupting family order.

**Withholding thoughts and feelings**

The purpose of withholding thoughts and feelings is to aid the participants in managing their inter-personal relationships and emotional well-being. The women in this study who withhold their thoughts and feelings from their family want to avoid stressful confrontation to maintain a harmonious atmosphere within the home. It can be seen that marital status and motherhood are determining factors influencing whether they withhold thoughts and feelings.
Single women

A distinction can be seen between single women and the other participants in this study. Single women are in a different social position and unlike their ever married counterparts; they are expected to always be taken care of by their family. Confidence and security is fostered by their position within the family, so they do not have to withhold their thoughts and feelings in order to manage the social aspects of their life:

'I don't worry about what I say to my family. If I don't feel well or I don't like something, I just say it. Why shouldn't I be able to express what I feel?' Marwa (A-S)

Instead of keeping their thoughts and feelings to themselves to avoid confrontation, these women fearlessly voice their opinions and expect their family to accommodate them. In fact, they are able to use their illness as an excuse to ventilate their feelings. This provides them with an emotional outlet that their ever married counterparts do not enjoy.

Married women

All married participants hoped that by withholding their thoughts and feelings, they could better manage their relationships with their husband. They did not express their true thoughts and feelings about their condition to their husband because they were sensitive to not being able to fulfil his conjugal needs, such as, sexual relations, affection and companionship. They did not want to give their husband any excuse for withdrawing from them. But when the husband was home and spoke only to the children about the events of the day rather than directly communicating with the participant, she sadly concluded that her husband no longer cared about her. Suppressing their feelings caused these women great emotional distress:

'I don't understand why he (husband) can't come into my room and ask me how I feel. Why does he always ask my children; how do they know? He's just avoiding me; he doesn't want to hear about my condition anymore. So, when I see him, I keep my troubles to myself.' Sabra (C-M)

Also, in order not to over-burden their children with worry, they did not discuss their fears and concerns with them. They believed that their children had enough domestic responsibilities without being overburdened with their mother's emotional needs. Nevertheless, the married women (15) who have older daughters over the age of 12 did transfer their hostile feelings they felt for their husband onto their children. Rogaiah expressed how she felt when keeping her feelings to herself as 'a balloon that may explode at any minute'. When asked to describe a particular incident, she states:

'... Like when I hold myself from answering back on my husband's criticism or his family's dissatisfaction about my children's behaviour or my lack of involvement in family affairs. I always kept quiet and never answered them back to avoid any family argument; I realized I shouldn't have because I ended up turning on my children. I know that I'm wrong, but they are my
Although these women realized that they were being unfair to their children, they did not want to further alienate their husband by arguing with him over his every complaint and criticism when they needed an emotional outlet to vent their feelings.

Previously married women

Unlike their married counterparts, previously married women no longer have a husband to consider; but they do resort to withholding their thoughts and feelings from members of the family that they move in with after their marital status has changed. Sixteen out of 21 of these women had to try to fit into a new household and attempted to make the best of a strained situation by not engaging in arguments with their host family. These participants complained how their host family no longer considered them to be independent adults making their own choices, but rather as dependent older children needing guidance. They expressed resentment at their loss of autonomy while simultaneously feeling guilty for being a burden on their host family’s limited resources. Rather than arguing with their host family about their rights to make their own decisions, these women began to withhold their thoughts and feelings, especially about issues relating to their own children.

Similar to their married counterparts, previously married women hoped to maintain good inter-personal relationships with relatives by silently suffering criticism. By neither voicing their thoughts nor feelings they hoped to maintain peace, harmony and security within the host family. Yet, when it became unbearable to harbour all of their negative feelings, they transferred these hostile feelings to their children. Withholding thoughts and feelings may manage inter-personal relationships amongst members of the host family; however, it caused friction in the mother-child relationship when these women are forced to side with members of their host family against their own children. They express feelings of guilt when they do not defend their children against what they see as unfair criticism and bias, but believe they do not have a choice in the matter because they are ‘guests’ in someone else’s home. When they transfer their hostility away from the unjust relatives to their children, they eventually jeopardize their relationships with their children:

'I love my children and I don’t want them to hate me, but I can’t stand listening to my family’s complaints about them. In my heart I know that their complaints are not always fair, and it angers me to hear them. But I must stay quiet. They make me feel that I must take their side and reprimand my children just to keep peace in the house. Although we are part of the family, we are still only guests and must be careful.’ Rehab (D-D)

In short, previously married participants explained that their reason for withholding thoughts and feelings were based on their attempts to maintain peace and equilibrium within their host family. They knew they had no control over their disease, but they believed they could ease family stress by not revealing their worries and fears to them. However, by trying to spare their family from
unnecessary emotional hardship, they actually caused themselves greater emotional distress. Over a period of time, it became more difficult for these women to participate in their family's social world; and their personal life became more confined to the experience of their illness. In their attempts to manage the social aspects of their life by withholding their thoughts and feelings from their host family, they ultimately became uncommunicative and unsociable.

Participation and withdrawal from family social activities

For all the women with ESRF, regardless of age, marital status or motherhood, participation and withdrawal became a way to manage their competing social demands and medical restrictions while aiming to maintain the social and health aspects of their life. These women had to join in their families' social activities which included meal preparation and all family events that traditionally continue through the early morning hours (parties and weddings), yet they had to maintain their health. They felt compelled to participate in order not to isolate themselves or offend their relatives:

'I shouldn't go to my relative's home because of all the food, tea and coffee they serve, but I have to go because I am expected to take part in family gatherings. Everyone serves what they make and insists that I have at least a bite or two. They always say that 'just a little' will not harm me, but I know better.' Nariman (D-W)

Since women are expected to participate in all social and family gatherings, social pressure caused them undue anxiety. Even though they had justifiable health reasons for not sharing responsibilities, their relatives failed to understand the gravity of their illness and tended to think they were just being unsociable. In order to 'save face' and avoid criticism from relatives, these women made attempts to participate in social activities, but usually withdrew themselves from the family when they became too tired:

'I must go to family events. I don't have a choice. If I don't, everyone will think I don't care about them. So, I go and when I get exhausted, I try to find a quiet place to rest.' Farida (D-W)

In addition to the above, single participants used withdrawal to avoid discussions about their female relatives' plans for marriage and motherhood. They explained how difficult it was for them to remain a part of the social group when this was the topic of conversation. Rather than show disappointment in their plight and upset their relatives, they used their medical condition as an excuse to withdraw to another room:

'Many times I just get up and leave the room; if I feel anyone (aunts, cousins) is noticing, I pretend that I have to get something or sometimes I just say I have a headache.' Bayan (A-S)

Thus, all participants resort to withdrawal in order to manage the social and health aspects of their life, while attempting to maintain a balance between participation and withdrawal from family social activities.
Resignation and accommodation

Age was the main influencing factor in whether a participant can resign herself to her condition and eventually accommodate her chronic illness as a way of life. Those participants who have resigned themselves to their condition appeared to have greater ability to manage all aspects of their life.

All women under age 35 years

The participants under age 35, regardless of marital status, did not resign themselves to being chronically ill. None of these women could allow themselves to be resigned to their condition for fear of losing sight of their future goals. These young women still had hope for a transplant. Both the younger age groups (a) and (b) expressed hopes that their condition would improve and believed they could eventually lead a normal life in the future:

'Tm still looking forward to a transplant. I hope to travel to India to get one. Then, Inshallah, [God willing] maybe I can get back to my husband and have a family.' Sahar (A-MS)

The single participants in these age groups believed they still had time to fulfill their dreams of getting married and having a family and home of their own:

'I believe that once I have my transplant I can have a normal life and hopefully get married and have a family.' Marwa (A-S)

Their younger married counterparts already having a family, felt that a transplant could give them more years to raise their young children and see them grow:

'I hope to get a transplant so I can properly take care of my children until they get married, Inshallah [God willing]. I'm still waiting for a donor from the hospital.' Afrah (B-M)

All women under the age of 35 still maintained hope for the future. Due to their relative youth, they hoped for a successful transplant that would allow them to marry and have children; or raise their children.

All women over age 35 years

The participants over age 35, regardless of marital status, initially denied their condition and struggled to maintain their roles and relationships. They accepted that they could not expect a successful transplant when they saw that women of their age who had received a transplant eventually had to return to dialysis therapy. Once they finally decided that there was no use in holding on to the idea that they would return to their original state of health, most accepted their illness and treatment as their way of life. This realization helped them to resign themselves to their new way of life:
'What else can I do; I have to push myself through, no matter what I think, no matter how I feel and of course no matter how hard it is; this is my world.'
Abla (D-M)

Although resignation has been considered to be a passive and sometimes negative approach to managing an illness, the narratives illustrate how this outlook actually inspired 34 out of 35 of these participants (who are all mothers) to plan for their young children's future. Since they understood that the probability of obtaining a successful renal transplant was low, they no longer dwelled on the feasibility of this prospect. Instead, they turned their focus away from themselves and towards their children. They wanted to insure that their children would be properly taken care of and discussed these matters with relatives from whom they exacted assurances and promises that their children would be secure. Rather than feeling totally powerless for not having a role to play in their children's future, they had a sense of self-worth for still having some impact on their children's life.

Sixteen married women (not including those who are separated) over age 35 had an additional concern, unlike their previously married counterparts; they desperately wanted to maintain some kind of rapport with their husbands. They realized that worrying about their husbands taking a second wife and leaving them only worsened their emotional condition, causing a greater rift between themselves and their husbands. So, they no longer struggled with this reality and tried to show compassion and understanding for their husbands' position. Resignation enabled them to be sympathetic rather than indifferent or resentful of their husband, which helped to alleviate some of the strain in their marital relationship:

'I know now we (renal patients) have to learn to accept our life and live with it. We have to fit ourselves into the big changes that take place in our life. Since I became sick, I have experienced many situations. Like three years ago when my husband took another wife, I had a hard time dealing with that. I was fighting with my husband all the time, which was causing a lot of tension between me and him; but I realized that I was not able to provide for his needs. So to maintain a stable home for me and for my children, I just had to accept and let it go. I have to continue living.' Abla (D-M)

Most previously married women who had to move out of their homes and move in with their relatives, used resignation to aid their children in adjusting to their new situation. They tried to ease their children's confusion and anxiety caused by this uprooting by explaining that this was their destiny. These women wanted to emotionally support their children even when they were unable to defend them from criticism by the host family. Thus, this approach enabled them to sustain their parent-child relationship, as well as manage their relationships with their host family.

Resignation enables these women to embrace a more constructive perspective regarding all aspects of their life. Rather than denying their deteriorating condition and frustrating themselves with unreasonable expectations, resignation allowed them to accommodate the permanence of their illness which enabled them to manage their health and social aspects of daily living. Once these women resigned themselves to their condition, they attained more peace of mind which further enabled them to better manage their inter-personal relationships and
emotional well-being. Resignation helped these women to be more compassionate towards their family and understand how others are affected by their illness.

Prayer

In Islam, *dua’a* [supplication] can be made at any time, in any place and under any circumstances. Throughout the interviews, prayer was constantly invoked by the participants as they related their experiences and responded to questions. Since prayer is evidently a vital part of these women's life, which they depend upon for solace and emotional comfort throughout their management process, I feel it is important to address.

Analysis of the narratives shows the role that prayer and religious beliefs play in the life of all these women and how prayer and religious beliefs assist them in reconciling the competing demands between their practical responsibilities and emotional well-being. Prayer can be considered a tool used by all participants, regardless of age and marital status, in helping them to manage their feelings so that they can maintain constructive relationships with their relatives and acquaintances:

‘Every day I pray to Allah [God] to grant me strength, so that I’m able to fulfil my responsibilities as wife and mother. Every morning I pray for this day to be the day where I can complete the tasks I have not completed for some time because of my fatigue, headaches or weakness.’ Rabha (C-M)

All these women use prayer for inner strength to help them tolerate the deficiencies in their life. They pray to remind themselves to be patient and calm and to request physical strength and ability to perform their tasks. Prayer is not only used to manage their emotions, but to cope with their daily challenges and obstacles confronted while performing their practical responsibilities.

Conclusion

This chapter has shown how all participants regardless of age, marital status and motherhood, have tried to find ways to manage the health and social aspects of their life. It was seen how at times when attempting to manage these various aspects, the participants were placed in a precarious position of having to reconcile competing demands from different aspects of their daily life. When these competing demands were not reconciled, i.e. health demands versus social demands, these women were often prevented from fulfilling their family responsibilities.

Throughout this process, the main concern of these women was influenced by their desire and need to maintain a 'normal' life. It can be seen that once ESRF changed their physical appearance, restricted their physical ability and caused medical complications, their definition of normality had to be modified by the parameters of ESRF. Their definition changed to accommodate what they can actually do in the present and not what they used to be able to do when they were healthy. Thus, these women had to resort to various actions such as, denial and/or minimization, acknowledgement of their physical limitations and integration, forming new
relationships with fellow patients, trial and error, dependence of family members, withholding thoughts and feelings, participation and withdrawal from family social activities, resignation and accommodation, and prayer to accommodate the limitations of ESRF on their health and social aspects of their life. As illustrated in this chapter, each action employed by the participants was an attempt to manage their various needs depending upon personal factors such as age, marital status, motherhood and available resources. There were times when one of these specific actions satisfied several aspects. Since the overall health of these women fluctuates, their efforts to maintain normality is an ongoing process and they must continue to find ways to balance competing demands that they encounter each day.
PART IV
DISCUSSION and CONCLUSION
Chapter Twelve
Impact of ESRF on Saudi Women's Everyday Life

End stage renal failure (ESRF) has an extensive impact on Saudi women due to its chronic nature which pervades all aspects of their everyday life. Since this study explored the extent to which ESRF affected the economic and social aspects of these women's life, the structure of Saudi society is examined in this chapter, focusing on the socio-economic as well as the socio-cultural constraints on Saudi women suffering from chronic illness. In order to discuss how ESRF and haemodialysis (HD) therapy influences the health and various aspects of life for chronically ill Saudi women, I had to broaden my approach to gain a more comprehensive insight into the illness experience of these women. The illness experience therefore includes biophysical changes, emotional feelings relating to bodily changes, and the socio-psychological and economic impact the disease has on the sufferer's life (Radley, 1994: 3).

Similar to Conrad (1990), I regard the participants in my study as 'sufferers' in their world where roles and relationships are negatively affected as a direct result of ESRF. These changes have important social ramifications that are the centre of all social action and inter-personal interaction (Nettleton, 1995: 69). Thus, the term 'sufferer' compelled me to explore the 'subjective experience' of these women and examine 'the meaning of illness, the social organization of the sufferer's world, and the strategies used in adaptation' (Conrad, 1990: 1260).

Applying western theoretical approaches to Saudi women with ESRF

Various theoretical approaches to understanding chronic illness have been considered to determine their applicability to Saudi women's experience with ESRF. A structural approach and interactionism are two sociological paradigms that I found to be the most applicable to my study (see Chapter 2). The structural approach assumes that people are the product of a social system (Kelly and Field, 1998: 5) and examines illness as a disruptive factor in a sick person's life because it prevents him/her from fulfilling social responsibilities as defined by society, which is the basis upon which an individual identifies him/herself. This approach stems from Parsons (1951) 'sick role' theory, the forerunner to structural approach, which regards illness as fundamentally affecting an individual's ability to fulfill his/her social roles. My data suggests that the primary concern of the participants is the economic burden placed upon their family as well as the changes in their social status once they were inflicted with ESRF, therefore the structural approach is relevant to identifying the socio-economic constraints on chronically ill Saudi women's quality of life. It is important to recognize how the impact of the structure of Saudi society and its socio-economic institutions (see Chapter 4) affect the everyday life of Saudi women with chronic illness.

Since Saudi society imposes restrictions and creates disadvantages for the chronically ill, ESRF cannot be exclusively perceived as a medical problem of the inflicted Saudi woman; but rather a social problem as Reeve (2002) and Priestly (2003) characterized earlier in Chapter 3. Although I partially agree with Oliver's (1996) definition that disability is the product of environmental barriers and social oppression, as a sociologist (not a disablist), I cannot focus completely on the
structural cause for disability at the exclusion of the impact that impairment has on the everyday life of disabled Saudi women (Crow, 1996). As a researcher, I cannot confine myself to using this approach because of its rigid and limited viewpoint that not only construes illness at the macro-level: strictly from the perspective of society and its response to chronically ill persons; but also tend to characterize illness as acute and short-term. Thus, totally relying on the structural approach to understand the impact of ESRF on Saudi women would, as pointed out by Annandale (1998), disregard the long-term and permanent nature of chronic illness as well as the patient's perspective where he/she is an actor who is directly involved with her treatment.

Due to the shortcomings of the structural approach discussed above, I also considered the interactionist approach, which examines illness from the sufferer's perspective. The interactionist approach examines illness at the micro-level where the focus is on the individual sufferer's experience with chronic illness. Unlike the structural approach, it is not limited to the effects illness has on the social system or the impact that the social system has on ill individuals. This perspective on disability permits me to broaden my study to include both the public experience of disability as well as the personal experience of impairment for disabled Saudi women. Since the focus of interactionism is on the sufferer's perspective, I constructed the meaning of Saudi women's illness experiences by examining their routine activities and social interactions. In addition, I assessed their interpretation of their own actions and responses as well as their interpretation of their relatives and acquaintances' actions and responses towards them and their illness. As Annandale (1998) points out, this approach recognizes that an individual's self is shaped by his/her roles and relationships with others and that the self alters with these kinds of interaction. This approach enabled me to study the effects ESRF had on Saudi women's inter-personal relationships and the changes it made on their self-concept.

Although each approach is diametrically opposed in its focus, they are both relevant when examining the impact of ESRF on Saudi women. On the one hand, it is crucial to understand how Saudi society is structured to address socio-economic needs as well as how society shapes the identity of Saudi women and defines their roles and relationships. On the other hand, it is also vital to examine the perspective of the sufferer (Clarke, 2001), namely the meaning of Saudi women's experience with ESRF. Applying more than one theoretical approach is in accordance with sociologists such as Radley (1994), who have determined that one perspective is insufficient to fully understand health and illness as it applies to the society and the individual: '...we shall not rely upon only one perspective... the research carried out in this field does not.... exemplify one distinct approach' (p. 15). Therefore, both a structural approach and interactionism are relevant sociological approaches as I explored the impact ESRF has on Saudi women living in Saudi Arabia. I found it necessary to utilize a 'hybrid' perspective or what Clarke (2001) notes is an example of a research study that combined in a single analysis, both the macro-level and micro-level approaches.
Quality of life for Saudi women with ESRF

Defining quality of life has proven to be particularly tricky since the exact term is never used by the participants. When participants discuss the kind of life they presently have with ESRF, they refer to it by what they can no longer do; what they no longer have and what more they need. The standard by which they assess their quality of life depends on how they managed their life prior to the onset of ESRF compared to how they are able to manage it subsequent to the illness. Since they constantly compare what they used to be able to do with what they could no longer do, they perceive their quality of life as deteriorating. The participants' inability to perform activities of daily life in the same way as they did prior to ESRF affects their subjective well-being, which Waltz (1986) asserts is closely related to quality of life.

Another dimension is added to this definition when these women refer to their roles and inter-personal relationships and question whether they are satisfying. Miller's (2000) definition of quality of life considers engaging in social roles and having satisfying relationships as additional factors that add to a sense of well-being and enjoyment of life. In an attempt to gain a clearer understanding of their sense of well-being and enjoyment of life, I asked these women whether they were satisfied or content with their present lives. When this question was posed, some of the women responded with rhetorical questions, 'Is this life? ', 'Is this it?' I interpret these questions as an indication of their dissatisfaction with their present life.

In addition to the above, the participants define their quality of life with respect to their need for and availability of resources. Although these women do not use the term 'quality of life' in their narratives, this is what I interpret them to mean when describing the availability and their lack of resources. When resources are readily available and their needs are satisfied, they describe their circumstances in a positive way; but when resources are scarce and their needs are not met, their circumstances are described in a negative fashion (Brown and Brown, 2003; Drummond, 2000). Specifically, it is found that when their family receive some form of financial assistance from the State or private benefactors, their circumstances temporarily improve; but when the necessary financial resources are lacking, their circumstances are greatly diminished. An increase in economic resources directly affects their emotional well-being, which in turn, affects their perception that their overall condition or quality of life also improves. Thus, the participants' quality of life alters as their economic conditions change.

Saudi structural constraints on the quality of life of disabled Saudi women

The relevance of Islam and its major influence on Saudi social structure must be recognized when examining how it affects the everyday life of chronically ill and disabled Saudi women (see Chapter 4). Islam plays a dominant role in Saudi society and its structural function is to establish a complete way of life that conforms to religious tenets, rather than a series of rituals that are performed on certain occasions; thus the acts of worship are integrated into all areas of life (Jawad, 1998). I considered the spiritual and practical aspects of Islam when identifying socio-religious constraints on the quality of life of these women.
The first aspect addresses the spiritual needs of chronically ill Saudi women which have no constraints when it comes to salat [mandatory prayer] and dua [supplication]. Both types of prayer can be performed in their home. Even their relatives and acquaintances can offer them spiritual support by calling over the phone. The participants notice how their health improves with spiritual support and report feelings of comfort and overall well-being.

The second aspect of religion concerns the rules that regulate the practical details of everyday life. Since there are some socio-religious aspects of Saudi society that make it difficult for chronically ill and disabled women to manage their life, I have to agree with Reeve (2002) and Priestley (2003), that disability does not only stem from the biological aspects of illness, in this case, ESRF; but is also caused by 'social processes', e.g., socio-religious norms. A prime example of a socio-religious norm that disables these Saudi women from effectively managing their illness is the requirement that they should not go out of their homes unless accompanied by a mahram [males related to the female by a certain degree of sanguinity]. This restriction also underpins Saudi law that prohibits women from driving their own cars, because it is expected that their male relatives will drive them wherever they need to go. Although under normal circumstances the unavailability of a mahram to drive a female relative to her destination may prove to be inconvenient for her, it becomes a serious health issue for chronically ill Saudi women who must attend dialysis sessions at least three days a week. Since it is a health imperative that these women visit the dialysis centre at the appropriate time, despite this socio-religious norm, they have to travel by taxi with a female relative if their mahram is unavailable.

Chronic illness is not a problem that is exclusive to Saudi women with ESRF, but rather a social problem for Saudi society as a whole (Reeve, 2002; Priestley, 2003). The restrictions imposed by Saudi socio-religious norms upon Saudi women in general and chronically ill Saudi women in particular, also create dilemmas for their male relatives who find it difficult or sometimes impossible to meet these women's dialysis transportation requirements.

Based on the foregoing, I agree with Oliver's (1996) definition of disability based on structural barriers that cause social oppression and find that there is validity to defining the disability of Saudi women with ESRF from a structural perspective where Saudi societal structures are essential disablers. Although the Saudi State provides medical resources free-of-charge to all of its citizens, the JKC is the only referral centre in Jeddah equipped to handle dialysis therapy for large numbers of women suffering from ESRF. This is a major structural barrier for these women who report that distance and travel times, therapy schedules, lack of certain conveniences, insufficient numbers of nurses, and the difficulty of communicating with non-Arabic speaking nurses greatly affect their health condition and general well-being. In fact, distance and travel time is considered to be the most burdensome barrier of all since all participants live between 30 minutes to 1½ hours away from JKC. This amount of time proved to be onerous and physically exhausting, especially as 42 of these women had to repeat the trip three times a week. All of these practical constraints are barriers that chronically ill Saudi women have to confront everyday, that result in both physical and emotional discomfort which has an oppressive effect on their quality of life. In addition, they
undermine these participants' adherence to Islamic principles, which involve suffering, patience and reward, because these women must constantly struggle to maintain these attributes while facing the daily challenges of chronic illness and social oppression of disability.

Another socio-religious barrier facing chronically ill and disabled Saudi women has to do with the change in their living accommodation when their marital status changes, i.e., separation, divorce or widowhood. Since it is both a religious and social custom for Saudi women to live with a mahram, their quality of life was adversely affected because of the constraints that arose out of their change in living arrangements. These women recognize that being able to keep their independence, domestic authority and privacy are essential factors that allow them to maintain a good quality of life. However, most divorced, separated and widowed women no longer live in their own home and have lost their independence, domestic authority and privacy.

**Socio-economic constraints**

All participants are concerned about their lack of economic resources due to socio-religious barriers. These economic resources comprise of income, accommodation and transportation; three areas that have a huge impact on the quality of life for Saudi women with ESRF. These socio-religious constraints also compound their family's financial difficulties. It has been established that gender-based identity differences in Saudi society are based on religious values more so than the gender-based identity differences found in western societies (Walby, 1990: 91). As a Saudi woman living in Saudi society, I am conscious of the fact that within the traditional Saudi social structure, gender is the most prominent cultural characteristic that affects both economic and social resources.

In theory, Islam regards both men and women as equals in terms of status, rights and obligations, blessings and punishment. However, gender is the basis for determining what rights and responsibilities an individual has within the family since gender distinction in Saudi society is based on a 'patriarchal structure' that defines the cultural ideas on feminine or masculine identity (Walby, 1990: 90; Yamani, 1996: 82), and as with other societies, the ultimate responsibility for the care of the family is delegated to women (Doyal, 1995: 30). Within this cultural context of social structure, there is a strong link between Saudi society and the family and between the family and its members, which shapes their mutual expectations (Abd Al-Ati, 1977: 20). For example, a Saudi man has the right to insist that his wife take care of the domestic responsibilities; but he also bears the responsibility of providing the economic and non-domestic support for his wife and children. As the wali-al-umur [legal guardian], he is the head of the household where they reside, i.e., for the single women living with parents, the primary source of financial support is the father or brother; for married women living with their husbands, it is the husband; and for the previously married women, it can be either their father, brother, uncle or son.

Saudi men's responsibilities for their female relatives should not be mistaken for having absolute power over them. They have control over non-domestic affairs because they are responsible for 'protecting' the family and making all decisions regarding family matters, i.e., finances, education, marriage, living
accommodations in cases of divorce and widowhood and guardianship over orphans. On the other hand, Saudi women's responsibilities are within the domestic sphere. Thus, they have the right to make decisions concerning the upbringing of their children, run the household as they see fit, and allocate household funds according to their judgment.

The Saudi socio-religious structure that requires a legal guardian to be the primary source of income (see Chapter 4) can at times overburden him because he must stretch his funds that normally cover his family's daily living expenses, to also accommodate the additional expenses incurred by his chronically ill and disabled relative. Forty-three participants reported never having been employed and therefore not having any personal income. Thus, they have to rely entirely on the head of the household for food and clothing; yet there is no difference for the seven who do have some personal income, since they too must depend on their guardians for subsistence. The only difference between these two groups is that the seven women with personal income (see Chapter eight) are able to contribute to payment for transportation expenses to and from the dialysis centre. In fact, all women report that the greatest financial burden on their household is the cost of transportation to and from the dialysis centre since public transportation, which could provide an affordable service, is lacking. The participants constantly worry about this issue because they know that if there is no male relative available to drive them to and from the dialysis centre or no available funds for taxi service, they have no way of going for dialysis therapy. Thus, there can be no doubt that financial constraints impose a danger for the health condition of these participants.

As previously stated socio-religious constraints on accommodation also compound financial difficulties and pose a strain on everyday life for the entire host family because the participants must share limited living space. These financial problems arise when a change in their marital status, e.g., separation (but still legally married), divorce or widowhood, occurs that requires women and their children to move out of their home into that of their guardian (Table 8.1).

Out of the 42 ever married (married, separated, divorced and widowed) participants, 16 previously married (separated, divorced and widowed) experienced a dramatic change in their circumstances when they had to move out of their original homes and move in with a male guardian. Once their head of the household changed, e.g. from husband to uncle, their primary source of income also changed. Unlike their single counterparts who are expected to always remain in their father's home as long as they remain unmarried, these women witness a difference in their quality of life once they move in with a male guardian, who according to Islamic religion and culture is responsible for their care.

Out of these 16 previously married women, 15 had to bring their children with them when they moved in with their guardian. These women witnessed a growing resentment on the part of their host family since Saudi society places the economic responsibility for the children on the father and his family and not on that of the mother's family. This is the reason for the host family's complaint that they should not have to share their already constrained economic resources with the participant's children. The host family believed that the solution to this problem could be solved if the participants sent their children to live with their ex-husband or his family. However, all of these women wanted their children to remain living
with them; they only wanted their ex-husband to financially support their children so as not overburden the host family with additional expenses. Notwithstanding the patriarchal social structure of Saudi society that traditionally stems from Islam, men of lower socio-economic status (such as those previously married to the participants) are either unable to provide for their children because of the additional burden of a second family or they simply abandon their children. When asked why they did not pursue their legal rights in family court, the participants expressed their discouragement due to complicated court procedures, lengthy proceedings and frequent adjournments. These obstacles became prohibitive for these chronically ill and disabled women who depended on their male guardian to apply to the court and appear at scheduled times. Their guardian could not pursue their case indefinitely and eventually had to abandon the case. Thus, the legal process which is the institution for proper redress actually becomes a social barrier and not a viable solution for these women.

The five participants who are separated (but still legally married) from their husband and had to move out of their home were always reminded by their host family that they could still reunite with their husband and save all of them from bearing the financial responsibility of taking care of them and their children. This was not considered to be a viable solution for these women who did not voluntarily leave their home but were expelled from the home by their husband. These women did not want to resort to using the legal system due to the social pressure felt by all women in Saudi society, that is, to get married and remain married. Rather than suing in court to enforce their rights, which may give the husband an excuse for a divorce, these women decided to stay with the host family.

However, the five previously married women who were able to stay in their own homes because they had an older son living with them are able to maintain their status quo as the dominant figure of domestic authority within their home. Even though they depend upon their male relatives (living elsewhere) for economic support, they still have their privacy, domestic authority and independence. As was stated above, these factors enable these women to maintain some quality of life despite their health condition, which can also be interpreted as a sense of empowerment. It should be noted that the term 'sense of empowerment' is a western concept which is not actually used by the participants to describe how they feel as a mother and wife living in their own home. However, these women reported that the only time they asserted any power was within their own home. Thus, domestic authority can be considered to be the only form of power that women without education, employment or personal income can have in Saudi society.

Unlike the five previously married women who were able to stay in their own homes, the 16 who had to move into their guardian's home described the changes in their personal circumstances in such terms that could be interpreted as loss of a sense of empowerment. Although these women are blood-related to the host family, they always feel like outsiders who are living in someone else's domain. They have lost their domestic authority because the host family is in charge of domestic affairs. They feel a sudden loss of privacy when they must share their bedrooms with their children or other relatives. Consequently, all these factors that give them a sense of empowerment and a sense of independence erode over
time. I agree with Mackey (2002: 109), that the concept of independence is not a social objective that pervades traditional Saudi society, but rather a social value prominently placed in western societies. Yet, there is a key distinction when referring to responsibilities that arise out of specific family roles and relationships in Saudi society, i.e., wife and mother; since it is only through these family roles and relationships that Saudi women gain a certain amount of independence within the family structure that Priestley (2003) recognizes as a symbol of 'self determination and choice’ (p. 118). However, when a Saudi woman moves out of her own home and moves into her guardian's home, she must forgo her personal choices and relinquish her domestic authority to the host family. Thus, the independence she had once experienced as a wife and mother is now lost and her quality of life is greatly diminished.

All 12 of the separated/divorced women became separated or divorced after the onset of ESRF. This compelling data reveals that all of the separations and divorces are directly linked to women’s chronic illness. These report that the hardships and complications caused by their medical condition placed stress on their husband who eventually left them. The 21 married women who still live with their husband in their own home express anxiety about the possibility of a marital breakdown. Living with this constant threat of becoming separated or divorced adversely affects their emotional well-being as well as their health condition, and their quality of life dwindles day by day.

The data suggest that the economic burden on the family is the major cause for a diminished quality of life for chronically ill Saudi women. The socio-economic model of the traditional Saudi family perpetuates women’s socio-economic dependence on their male guardian and is incompatible with living in a modern society where the male guardian may be financially incapable of being the sole-provider. In addition, the traditional concept of extended family where members share a common household and resources so that they can easily coordinate social support becomes increasingly difficult if not impossible to manage in an urban setting. This is partially due to the modern lifestyle which includes nuclear families living in independent households, separated by distance. These factors prevent the extended family from sharing economic and social resources when each nuclear family lives apart from each other and thereby has to pay for its own accommodations. Despite these practical difficulties found in modern society, the Saudi family tries to maintain its traditional values in its roles and responsibilities. However, it is important to acknowledge these structural changes in the Saudi family in order to identify the needs of its members and make the necessary provisions for them. The socio-economic model of Saudi society based on traditional family rights and obligations where women's socio-economic dependence is placed on their male guardian can no longer be borne totally by the family, especially those extended families that have chronically ill relatives. It is especially urgent for the women in my study, who come from low socio-economic families, for the State to become the primary source of economic resources and social support services in order to assist their family in sustaining its role and responsibility.
Socio-cultural constraints on maintaining normality

The primary goal for Saudi women with ESRF is to maintain a semblance of normality in their life by trying to preserve their family care-giving roles and relationships despite medical complications, limitations in physical ability and changes in physical appearance due to ESRF. However, their concept of normality changes when they realize that what they can actually do now is very different from what they used to be able to do when they were healthy. They can no longer define being normal as being healthy. Similar to chronically ill participants in Thorne's (1993) study who defined being normal as 'not in a healthwise way, but in a lifewise way' (p. 56), Saudi women with ESRF also define being normal according to their ability to manage their daily life. Their attempts at maintaining 'normalization of intrusiveness' of ESRF with respect to their interactions and social relations become an 'uneasy equilibrium between... 'abnormalization and normalization of life" (Strauss, et al. 1984: 79-80). A prime illustration of this is when the participants are unable to control the intrusiveness of their medical regimen (dialysis schedule, time spent at the dialysis centre and transportation), and therefore were never able to normalize this aspect of their life. They discover that their social and emotional aspects actually contend with their health needs for time, energy and available economic and social resources. Radley (1994: 152) refers to this struggle between these various aspects of life as 'competing demands' when failing to meet them interferes with the attempts of the chronically ill to maintain a normal life. An example of this is found in participants' attempts to perform their various family care-giving roles and relationships, as well as spending long hours at the dialysis centre to maintain their health (see Chapter 10). Since 'normal' life for Saudi women with ESRF alters according to their physical condition, emotional well-being and personal circumstances, the concept of maintaining normality constantly changes to reflect the fluctuation in their ability to manage daily tasks and the accommodations they make to meet the medical and social demands in their life. These accommodations are in reality what Radley (1994) refers to as 'purposeful activity that is directed towards some end' (p. 150).

As with respondents in Williams' study (1993: 18, cited in Bury, 1997: 132), the women in my study also express having difficulties in managing their competing demands due to the lack of support resources that stem from their low socio-economic status. I agree with Bury (1997: 131), that the level of available support resources from society is as crucial to the success of chronically ill women managing their competing demands as the actual ability of the chronically ill individual to perform a task. Thus, personal circumstances which include material factors, such as, social networks and social support (p.131) or financial and social resources (see Chapters 8 and 9), must be provided to chronically ill Saudi women and their family in order for them to maintain a normal life.

In Saudi society, the family has traditionally been the primary source for both economic and social resources and continues to be so (Yamani, 1996). Acquaintances occasionally supplement the family's economic and social resources; and the State lends limited economic support but no social support (Figure 8.1). It is the socio-cultural norm for Saudi women, in general, to rely upon their family members for support; but dependence on relatives for assistance increases for those women suffering from chronic illness. It is easy to understand
the dynamics of providing economic and practical support; however, it becomes more complicated when the resource comes in the form of inter-personal relationships where the source (family) is itself the resource (inter-personal relationships). The participants do not understand the extent to which their inter-personal relationships with family members have become strained when their need for practical support continues over a long period of time. Even though they have no choice but to rely on their family, their over-dependence on them constrains their inter-personal relationships. These women emphasized the importance of inter-personal relationships to their emotional well-being and described them in terms of companionship, comfort, encouragement and reassurance. Thus, I include inter-personal relationships as a resource under the types of social support where it has been determined that the family is the primary source (Figure 9.1).

It is crucial to reiterate that the basis for their inter-personal relationships is founded on Saudi socio-cultural norms borne out of the Islamic belief system, because failure to fulfil any of their roles is not only detrimental to their family relationships, but also to Saudi society as a whole (see Chapter 4). For example, the text found in Saudi's Basic Law (Article 40), states that 'the family is the basic unit of Saudi society...' (Yamani, 1996: 268). Accordingly, Saudi women are the foundation of the family institution and it is through their numerous roles that they maintain strong family ties. Since all participants, regardless of age, marital status, motherhood, income and health condition, need social support to manage their lives, any constraints on their inter-personal relationships are considered to be detrimental to their quality of life. Unfortunately, society's expectations of Saudi women are extremely burdensome on those who must face the obstacles and limitations imposed by chronic illness; thereby, turning what is considered to be positive aspects of Saudi society, into socio-cultural constraints that hinder their attempts to achieve normality.

**Social expectations and physical ability of chronically ill women**

All participants, regardless of age and marital status, express a willingness to perform their daily duties, but the limitations in their physical ability force them to accommodate the changes that occur and adjust to their new way of life. Issues relating to hidden conditions such as fatigue, body pain and listlessness are identified as being the most difficult for them and their family to understand and accept. Although these effects are real, the symptoms seem to be non existent to others and their invisibility reinforces their family's doubts and disbelief. Under these circumstances, the participants in my study fit in to Goffman's category of 'discreditable' persons (1963: 14) where in order to avoid being labelled lazy and antisocial; they have to participate in family activities regardless of fatigue and discomfort. Similar to Thorne's study that illustrates how 'suffering silently' by avoiding complaining caused the discreditable person 'emotional distress' (1993:73); by withholding thoughts and feelings to manage their inter-personal relationships, the women in my study report how stressful it is to sit amongst family members and pretend that they are feeling well when in fact they only want to be in bed. When they eventually have to withdraw from these social activities and retire to a more quiet area of the house, they still worry about how their relatives will react.
Due to changes in cognitive ability caused by physiological changes associated with ESRF (e.g. uraemia, a waste build-up in the blood), all participants regardless of age and marital status, suffered from impaired judgement, lack of concentration and loss of memory (Falvo, 1999: 317). However, it was the ever married participants who were in a constant state of anxiety because they were unable to make simple decisions concerning family obligations and daily domestic chores. They felt unreliable and undependable and were beset with self-doubt. These cognitive changes caused these women to overly depend on their relatives for practical support which in turn, placed great strain on their inter-personal relationships.

Since the two most important family care-giving roles in Saudi women's lives are found in marriage and motherhood, all ever married women are the most affected by their physical changes. These changes seriously affect marital and maternal relationships that result in loss of intimacy with their husband and loss of domestic authority over their children. As discussed in Chapter 10, loss of intimacy caused all married women to become insecure about their marital status and fear the day their husbands may leave them or marry a second wife; and loss of domestic authority caused all mothers to feel guilty about relinquishing their domestic responsibilities and compelling their children to assume their duties and tasks. They responded to these disruptive factors by withholding thoughts from family members and internalizing feelings so as not to further burden them with their emotional problems. Furthermore, due to the 3 days a week HD therapy schedule, these women could not always be available for their children when they returned from school and were unable to meet their family social obligations. This loss of communication and social participation increased their sense of isolation.

A main distinction based on marital status is found between the eight single women who are daughters living in the parental home and the 16 previously married women who had to move in with their guardians. Unlike their previously married counterparts, single participants have always been the recipients of care rather than primary care-givers and their roles as daughter, sister and aunt affect their family's expectations of them. Socio-cultural norms do not place the burden of domestic responsibilities onto young single women who live with their parents, so they do not experience the enormous pressure shared by their previously married counterparts. The only identifiable losses to single women's roles and relationships are loss of communication and/or social participation when they cannot share their thoughts and feelings about their 'hopes for the future' or they are not well enough to engage in social activities.

Cultural standards of beauty and appearance of chronically ill women

In addition to limiting these participants' physical ability to perform their domestic and social responsibilities, ESRF diminishes a woman's physical appearance which is highly valued in all societies. Shakespeare (1996) points out how in western cultures, disabled people have 'serious problems with self-image' as 'sexual confidence is so centrally about beauty, potency and independence' (p. 193). This also applies to disabled Saudi women where an important aspect of being a successful wife is to remain attractive to her husband (or for single women, it is important to be attractive in order to receive proposals of marriage). A Saudi wife with ESRF is ever mindful that her husband might be encouraged to
marry another woman if she is unable to have children or 'enough' children (especially sons); or she is unable to sexually gratify him (Badawi, 1972: 7). Under these circumstances it is acceptable for the husband's family to advise him to take another wife (Mackey, 2002: 153). Marriage serves many purposes in Islamic culture: '...emotional and sexual gratification; ...a mechanism of tension reduction, legitimate procreation, and social placement; ...an approach to interfamily alliance and group solidarity' (Abd Al-Ati, 1977: 54). Thus, it is frowned upon for Saudi women to be seen unkempt by female family members and acquaintances. However, this burden of always looking one's best and being on one's best behaviour places an overwhelming strain on chronically ill Saudi women.

It is the cultural norm for Saudi women to look well groomed and appealing in the home at all times and they are not expected to be caught 'off guard' if and when female visitors arrive. Since it is the cultural norm in Saudi society for women to recommend another as a prospective wife to a male relative, it is always important that Saudi women maintain a good appearance, manners and hostess skills. Importantly, these qualities remain under scrutiny even after women marry. They are aware that marital harmony is largely based on in-laws' continued approval of them, so by attempting to control or hide 'intrusive' symptoms of their illness (Strauss, et al. 1984: 80), e.g., covering bruises on their arms with long-sleeved garments while in the presence of family and acquaintances, etc., (see Chapter 7), these women are attempting to maintain normal inter-personal relationships. However, it becomes almost an impossible task for them when they are frequently suffering from the side-effects of dialysis that greatly diminishes their physical appearance. When these women feel that they no longer fit the social standard of beauty and fitness, they become ridden with shame and guilt.

**Loss of self**

As discussed in the above sections, the 'dual demands of bodily change and cultural constraints' (Radley and Green, 1987: 179), ultimately shape and define Saudi women's self-perceptions. When addressing how the participants perceive themselves with regard to their family members and acquaintances, it is important to understand the socio-cultural expectations that are traditionally held by Saudi society. Islam highlights the importance of the family in terms of identity and purpose of the individual and regards the family to be the most essential institution of society. Based on this Islamic premise, the Saudi social structure revolves around the Saudi family. Loyalty to the family is paramount to any other type of relationship, except to that of God (Yamani, 1996).

Socio-cultural norms define roles and relationships of Saudi women based on various demographic factors that shape family expectations of them. The most influencing factors in this study include marital status and motherhood. These two factors dominate the concerns of all participants because of the socio-cultural norms of Saudi society which are 'governed by Islamic principles' (Anwar, 1987 as quoted in Roald, 2001: 87); where wife and mother are the two primary roles that Saudi women are expected to fulfil. (NB: Only one of the ever married participants has no children). Even the eight single participants concentrate their thoughts on the possibility of marriage and motherhood. It is marriage and
motherhood and not age which are the primary factors that influence how people in Saudi society treat women. When a woman is married and has children, she is treated as an adult regardless of how young she may be; whereas, much older women who have remained single are treated as young dependents.

In Saudi society, the role of wife and mother is held in the highest esteem and women who function in these capacities hold a high status in society: 'for the female, her role as wife and mother is considered the most sacred and essential one' (Badawi, 1975: 141). The social expectation that places family before all else is based upon the assumption that a woman is capable of performing many responsibilities on a daily basis. According to socio-cultural norms, this may be reasonable for a healthy woman, but can be daunting for a chronically ill and disabled one. However, Saudi society's definition of a successful wife and mother does not coincide with the disabling realities that befall chronically ill Saudi women that require long-term medical treatment which forces them to abandon their domestic chores and social obligations (see Chapter 10). Their inability to meet society's expectations ultimately increases the stress and disappointment these women feel when they believe that they have failed their family. Eventually chronically ill and disabled Saudi women experience a change in their status within the family. As their condition impedes their ability to perform their family care-giving roles, their position within their family is vulnerable and their identity is no longer in tact (Shakespeare, 1996: 202). Thus, Saudi socio-cultural norms regarding women's family care-giving roles and relationships place great burden on chronically ill and disabled Saudi women.

The primary aspect of Saudi social structure is to uphold the family and its traditions. However, it falls short of this goal in the face of a 'disruptive event' (Bury, 1982: 168), such as chronic illness, that changes how family members perform their traditional roles and responsibilities. ESRF not only disrupts the life of the women who become inflicted with the disease, but also disrupts the life of each family member who has a direct role and responsibility for providing them with social support. The disruptive factors that arose out of this disruptive event that have changed their family roles and relationships and eventually sabotaged their efforts to maintain normality in their life include 'loss of marital intimacy', 'loss of domestic authority', and 'loss of privacy'.

Charmaz's (1983) term, 'spiralling consequences', accurately characterizes these losses that occur over time as Saudi women with ESRF lead a physically restricted life that eventually leads to social isolation and anxiety. When analyzing the physical and psychosocial changes that occur in these women's lives, I was able to relate their experience to what Charmaz refers to as the 'loss of self'. The socio-cultural norms that define Saudi women's identity based on traditional roles and relationships ultimately constrain chronically ill Saudi women from having a positive self-concept that would enable them to maintain fulfilling inter-personal relationships with their family members. Their negative body-image and low self-esteem also result in a diminished self-concept. This is revealed during the interviews in their homes when they attempted to conceal their bruised arms with long sleeves and their paleness with cosmetic make-up. It is these signs of visibility that Goffman (1963) says distinguish those disabled individuals who are 'discredited', from those who are 'discreditable' (p. 14). Goffman's 'plight of the discredited' (p. 14) is similar to the experience of the participants in my study in
that they manage their social demands as well as their emotional well-being by making a 'direct attempt to correct' (p. 19) by minimizing the visible signs of illness through the use of cosmetics and long sleeves. These women are in constant struggle with their identity according to Saudi socio-cultural norms and their negative self-concept based on their changed condition. The conflict between Saudi socio-cultural norms regarding women's roles and relationships and the realities associated with chronic illness obstructs chronically ill Saudi women from reconstructing a new positive identity.

Loss of privacy is a major disruptive factor affecting the 16 previously married participants who had to move out of their home and move into the home of a guardian. Once they had to move in with their guardian, their roles and relationships with their children and relatives were reshaped and they no longer possessed any domestic authority over their environment. They were forced to become more dependent on their relatives and had to accept the host family's decisions. Like their married counterparts, they felt compelled to withhold thoughts and internalize feelings.

All disruptive factors eventually increase participants' dependency on extended family and in turn decrease their autonomy. With the onset of ESRF, their social roles are altered and their relationships are jeopardized. I characterize this phenomenon as a loss of control over those aspects in life that define who Saudi women are within family and society that ultimately result in a loss of self. Yet, at times these women report that some days are better than others because they experience some success while performing their responsibilities and interacting with family members. It is during these times that they perceive themselves in a more positive light and are able to make sense of the illness (see Chapter 7). Their self-perceptions fluctuate as they constantly struggle to balance their medical regimen with their regular routine domestic activities. Thus, perceptions about themselves and their illness can vary daily depending on whether they have a 'good' or 'bad' day. Therefore, the process of making sense of the illness is ongoing and Saudi women suffering from ESRF must persevere in their endeavours to adjust to their altered way of life.

**Conclusion**

In order to examine the impact ESRF has on Saudi women's everyday life, it was useful to utilize both the structural approach and interactionist approach to identify the socio-cultural restrictions and the socio-economic disadvantages imposed upon Saudi women; as well as examining the illness experience of Saudi women with ESRF. The structural approach was relevant to identify the various ways in which the Saudi social system is an essential disabler that impedes chronically ill women from fulfilling their social responsibilities. Saudi societal structures based on religious values and traditional customs are gender-based, such as, needing a mahram escort when entering the public domain, needing a male driver for transportation service, and depending upon a male legal guardian for income and accommodation. These socio-cultural restrictions which dominated their life simultaneously placed socio-economic constraints on them. On the other hand, interactionism was also a valid approach in order to understand the subjective
experience of Saudi women with ESRF with regards to loss of self, normality and quality of life.

Socio-cultural norms clearly define Saudi women's family care-giving roles and relationships that reinforce their family and society's expectations of them. However, ESRF as a chronic illness disrupted their roles as wife and mother when their physical limitations and psychosocial changes no longer allowed them to manage their everyday tasks or maintain normality in their life. Their inability to uphold traditional socio-cultural norms prohibited Saudi women with ESRF from having a positive self-concept. Thus, their loss of control over those aspects in life that define Saudi women's identity ultimately resulted in a loss of self.

The socio-economic model of the traditional Saudi family perpetuates women's socio-economic dependence on their male guardian regarding income, transportation and accommodation. In addition, Saudi women require their relatives to provide them with social support in the form of inter-personal relationships and practical support. The lack of economic resources due to their low socio-economic status, coupled with chronic illness placed a financial burden on Saudi women with ESRF and their family. This over-dependence on their family had a direct impact on their ability to manage their everyday life and resulted in a diminished quality of life.
Chapter Thirteen
Conclusions, Policy implications and Reflections

The primary aim of this study was to examine the impact end-stage renal failure (ESRF) and haemodialysis (HD) had on the everyday life of Saudi women. This study critically explored Saudi societal structures to determine to what extent they disabled chronically ill Saudi women; and how gender-related issues affected the religious, medical, economic and social aspects of their life. This study examined how the lack of availability of sources and resources diminished the quality of life for chronically ill Saudi women; how ESRF had disrupted their family care-giving roles and relationships; and how Saudi women's perceptions of themselves and their illness affected their ability to manage their everyday life.

A further aim of this study was to assist policymakers in creating and implementing new policies and procedures that will meet the global standards for improving the quality of life for chronically ill and disabled women in Saudi Arabia. The need for greater social awareness within Saudi society is discussed with the intent to promote a national policy that accommodates the needs of chronically ill Saudi women and eliminates socio-economic barriers that disable them from managing their everyday life.

Since there is no literature on the impact of ESRF on Saudi women before this study was conducted, this study also aims to inform western medical sociology. Western sociologists can compare the differences between the effects that chronic illness and disability have on western women with that of Saudi women to determine the extent that socio-cultural norms shape their illness experience.

In order to fulfil the aims of this study, a qualitative method was implemented. The participants were systematically selected (Arber, 2001) for qualitative interviewing in order to explore their illness experience. This systematic selection procedure was used to obtain a fixed sampling interval from all Saudi women with ESRF who were receiving haemodialysis treatment at Jeddah Kidney Centre (JKC) which allowed me to get a more evenly spread sample. My interview sample consisted of 50 Saudi women undergoing haemodialysis at JKC between the ages of 24-59 years old, who primarily belonged to a low socio-economic status and had little or no formal education.

The grounded theory approach (Glaser and Strauss, 1967) was utilized to comparatively analyse (Strauss and Corbin, 1998) the data obtained from in-depth interviews, observations and field notes. This analytical method for investigation included developing theoretical concepts, categories and coding. To better understand the participants' illness experience and social identity, I proceeded to examine the emerging themes from their narratives (Giddens, 1991; Somers, 1994).

Key Findings

In order to have a complete understanding of the impact that ESRF has on the daily life of chronically ill Saudi women, both micro and macro level issues had to be examined. At the micro-level, understanding the illness experience depends on
examining how the individual adjusts to the 'disruptive event', i.e., ESRF, which involves how practical management of daily life and social relationships are altered. The interactionist approach was used to explore the various effects chronic illness has on Saudi women's life which takes into account both sociological as well as biological factors that affect the illness experience and examines all aspects of their life. It should be recognized that as the body changes with chronic illness, so do the sociological concepts of self and identity of the sufferer. The whole illness experience of Saudi women with ESRF includes their bodily changes, their socio-psychological as well as their economic aspects of life.

In addition, it was essential to consider more macro issues relating to how Saudi social structure shapes the identity of Saudi women and defines their roles and relationships. This structural approach includes issues concerning how ESRF causes a breakdown in the Saudi family structure by preventing Saudi women from fulfilling their family care-giving roles and responsibilities as defined by their society. This thesis has shown the importance of understanding the socioreligious traditions of Saudi society in relation to women in order to understand the identity of Saudi women, in general, and chronically ill and disabled Saudi women, in particular. The identity of Saudi women is shaped by a traditional society that is greatly influenced by Islam, which teaches that family is preeminent and women's family care-giving responsibilities are paramount to all other duties; and it is through these numerous roles that women maintain strong family ties. Since Saudi women are the bedrock of their family and vital to the foundation of Saudi society, failure to fulfill any of their roles is seen as detrimental to their family relationships. As chronically ill women's abilities to manage these roles and responsibilities diminish over a period of time due to their illness, their identity is adversely affected.

Socio-cultural constraints on Saudi women with ESRF

My conclusions regarding disability and identity are partially based on the social model that defines disability from a structuralist perspective that disability and identity is created by a social and political process (Swain et al., 2003); thereby placing the responsibility on societal structures (Priestley, 2003). The main premise is that an individual's identity is based on his or her social, cultural and historical context (Greenwell, 2003). In the light of this, I conclude that Saudi cultural norms based on gender, such as, prohibition of driving for women and dependence on male legal guardians for every aspect of their life, are structural barriers that disable Saudi women with ESRF from effectively managing their illness experience. Socio-cultural norms that shape their identity by defining their roles and relationships based on their marital status and motherhood are also social barriers for chronically ill women who cannot meet these societal expectations. Their inability to fulfill their roles and relationships due to disruptions caused by chronic illness undermined their status within the family, distorted their self-perception and ultimately threatened their identity. Thus, Saudi women with ESRF were unable to effectively manage their life, which in turn affected the equilibrium of their family.
Lack of financial support resources

The lack of availability of support resources, especially financial, negatively affected the quality of life and well-being for Saudi women with ESRF. Since they depended on resources to manage their lives, the availability or lack of resources had a direct impact on whether these women could manage their everyday life. Any constraints on financial resources (income, transportation and accommodation) not only greatly diminished their quality of life but were also life-threatening (see Chapter 8).

Income: Since Saudi women with ESRF do not have personal income, they must depend on their legal guardian for financial support. Their lack of personal income stems from the traditional Saudi custom that has encouraged women to stay at home and care for the family rather than seek education and employment. However, the lack of family financial resources is due to the low economic status of their legal guardian who does not have sufficient funds to pay for necessities that ease their illness condition. For example, these women cannot pay for domestic help which would provide them with better care; and when family members are unable to take care of these disabled women on a daily basis, they must fend for themselves even though their physical limitations greatly impede them. When these women force themselves to perform domestic chores, their condition weakens and their health is further jeopardized.

Transportation: Since there is no available public transportation for women in Saudi Arabia, and women are not supposed to travel alone, women with ESRF are forced to depend on their male relatives who may not be able to take them to their scheduled dialysis sessions. The fact that these women neither have income of their own to cover their transportation expenses, nor do they have a driver to take them to and from the dialysis centre, means they may end up forgoing their treatment. Every time these women miss one dialysis session, their life is threatened. Once they miss a dialysis treatment, their condition becomes critical and they must go to the emergency unit for immediate medical care. Thus, readily available transportation is not a matter of convenience, but an essential service for these chronically ill women.

Not only is the lack of transportation a major issue, travel distance is a crucial factor that needs considering. It must be kept in mind that women with ESRF must make trips to and from the dialysis centre three times a week for the rest of their life or until they receive a renal transplant. By the time they get to the dialysis centre, they are in a state of anxiety and exhaustion which aggravates their condition and further weakens their body; and after 4 hours of strenuous treatment, they have to make a tiresome trip back home. Thus, travelling becomes a major strain on their condition that negatively affects their health.

All participants live in the outskirts of Jeddah; far from JKC which is the only referral medical facility that provides haemodialysis. They reside in areas that do not have access to main roads where taxi services frequent. Since they are physically unable to walk to a main road, they have to rely on a male relative to obtain a taxi for them. The time and extra expense it takes to get a taxi to drive to their front door is a nerve racking experience that jeopardizes their health (see Chapter 9).
Accommodation: Due to the socio-religious custom that requires Saudi men to be responsible for the women in their family and the Saudi social norm that prohibits providing rented housing to women without a guardian, Saudi women with ESRF who no longer have a husband must move in with a male guardian (see Chapter 8). Unfortunately, the legal guardian's house or family is not adequately equipped to handle the various problems that arise from chronic illness, and therefore they are unable to properly care for their relative with ESRF. A living environment with limited space and comfort does not permit extended families to provide their chronically ill relative with the required privacy conducive to rest and relief. Trying to provide proper accommodation for women who will remain ill for the rest of their life is a burden that families cannot sustain interminably.

Lack of practical and inter-personal support

The lack of availability of practical support and social support through interpersonal relationships also negatively affected the quality of life for Saudi women with ESRF (see Chapter 9). Their over-dependence on the family network for these resources disrupted the delicate balance between rights and responsibilities of family members.

Practical support: In Saudi society, practical support is gender-based and is divided into domestic and non-domestic support, whereby female relatives provide the former and male relatives provide the latter. Since this type of support is provided only by the family network, these women heavily depend upon their relatives for practical support; and if the family network is unable to meet their needs, there is no other recourse (Figure 9.1). Due to the long-term nature of ESRF, their dependence on relatives for practical support increases. Unfortunately, this practical support tends to decrease with time, which ultimately impedes their quality of life.

Inter-personal relationships: The chronic nature of ESRF jeopardizes interpersonal relationships of Saudi women with ESRF because their financial and social needs excessively burden their family members. These women need their family's sympathy and understanding, but when the family network becomes overly stressed by mounting responsibilities stemming from chronic illness, their emotional support which includes comfort, encouragement and reassurance dissipates.

The disruptive factors of ESRF, such as, physical limitations, psychosocial changes and changes in physical appearance, diminished the family care-giving roles and relationships of chronically ill Saudi women that in turn, sabotaged interpersonal relationships and impeded their ability to maintain normality in their life. Unable to complete daily domestic tasks, women with ESRF had to relegate their responsibilities to other members of the family. Physical limitations prohibited them from performing their roles as wife and mother which resulted in their loss of parental authority and marital intimacy. As dependency on their family network increased, their autonomy and privacy decreased. Eventually this loss of control over their life altered their self-concept leading to feelings of guilt and shame over not being able to fulfill their family care-giving roles and relationships. Eventually, these women suffered from a loss of self that required them to redefine their self-
concept and view of normality. Through this process of adjustment, perceptions about themselves and their illness also changed.

Policy implications

In order to influence future policy in Saudi Arabia regarding various issues related to chronic illness and its negative impact on the lives of Saudi women, I decided that I would accept an advocate's role on behalf of chronically ill Saudi women. I believe this position is not in conflict with that of an objective researcher and agree with Finch's assertion that the researcher should make an 'emotional as well as an intellectual commitment' to her participants (1984: 86). It is also not in conflict with the Saudi Kingdom's Eighth Development Plan of 2005-9, that sets forth as its goals the improvement of its citizens' living standards and quality of life, which includes the upgrade of health care and social welfare, as well as the development and improvement of women's welfare (pp. 25-9). Hopefully, my approach will assist policy makers to clarify issues that affect a specific segment of the population: the chronically ill and disabled Saudi woman; and influence them to implement appropriate programs that will improve their quality of life.

Since this Development Plan pays special attention to the area concerning the care of 'poor and needy' families (2005-9: 77), the economic constraints placed on the family of chronically ill and disabled women in my study must be addressed because economic constraints directly affect the availability of all types of social support, which ultimately impacts on their quality of life. The crux of the matter can be seen in women's concern for their family's ability to continuously provide them with the necessary social support despite the family's limited economic resources. When considering that these women fall into low socio-economic status groups within Saudi society, one may think that the burden of social support would shift to the State. The Development Plan recognizes that 'addressing poverty and improving standards of living remains, in the first place, the responsibility of the government' (p. 78), however, the structure of Saudi society still places the responsibility of care solely on the family. It should be noted that the traditional Saudi extended family, 'which used to provide various forms of social support and solidarity, is no longer the predominant family' (p. 315). It is, therefore, necessary to establish effective social security arrangements 'to create all favourable conditions for preserving cohesion of the family, raising its standard of living, and protecting its values' (p. 301).

The State also acknowledges that a large household size increases the family burden to meet the food, education and health needs of its members (MOEP, 2005-9: 185), and my study further finds that these problems are compounded for those families belonging to a low economic group who are additionally burdened with responsibilities associated with chronic illness. Thus, in line with the development plan to improve the 'performance of responsible agencies' and to 'integrate' the responsibilities of appropriate agencies (p. 302) in order to improve the quality of public services (p. 29), the Ministry of Social Affairs (MOSA) must assert its authority in providing the much needed financial support for these families. This financial support would include supplemental income for both the women with ESRF and their family members who provide them with financial and
social resources; and housing that is more accessible to the dialysis centre in order to decrease the travelling time for these women.

It is reiterated in the framework of the Eighth Development Plan (2005-9), that it assigns utmost priority to raising standards of living and improving quality of life (p. 31) and refers to 'enhancing participation of women, development of their capabilities, and elimination of obstacles to their participation' (p. 47). Within this context, the Development Plan aims to direct designated agencies to provide 'reliable support to all citizens in cases of emergency, illness, disability and old age' (p. 47). This general goal is important for chronically ill women who belong to the low socio-economic status, since my study specifically reveals how crucial it is for the State to provide appropriate permanent housing facilities for these women and their children that will enable them to live a more comfortable and normal life and also alleviate family hardship. This is a practical solution to this ever-pressing problem since MOSA is already providing public housing for the economically disadvantaged. In addition, since the Ministry of Health (MOH) oversees medical facilities, it can also include housing facilities near dialysis centres for these women and their children. This solution can avoid incidents like those that have been reported in a daily Saudi newspaper, Al-Watan (2005, issue 1626), where families of eight women with ESRF were forced to illegally abandon them at the hospital because the families no longer had the resources to properly tend to their needs. Even though these families could no longer provide financial or social support for these women, they were still forced to take them back by the police or face imprisonment. This illustrates how Saudi women with ESRF can no longer be treated as a private family matter; for it is now a social problem that affects Saudi society.

Since the lives of women with chronic illness and disability are being sustained for longer periods of time due to medical advancement, the family's limited resources are further depleted than ever before, especially when these women and their children have to move in with a guardian and his family. The imperative of the Eighth Development Plan to 'enhance the social security system and encourage institutions and individuals to undertake charitable activities' (MOEP, 2005-9: 47) and 'to provide social care services to local communities, with family care continuing to have special significance' (p. 80) supports my findings that in addition to financial support, a joint commitment by both the Ministry of Social Affairs and the Ministry of Health, should also provide these women with various home health care programs that would greatly improve their quality of life. These programs should include home peritoneal dialysis, visiting nurses and home aides who would come into the homes and provide domestic support. This type of assistance would relieve the rate of truancy amongst school age daughters who have been reported to stay at home to care for their mother; and would also relieve other female relatives from leaving their own family in order to provide these women with domestic support. A program that delivers hot meals directly to the homes would also be a vital social service for these women who find it difficult to prepare meals for themselves and their family. These home-health care programs would keep ESRF from dominating and interfering with these women's way of life, as well as allowing them to better maintain their roles and relationships since they would be able to spend more time with their family in their homes. In short, home-health care programs would provide a sense of normality for chronically ill women with ESRF and their family.
There are other practical needs that if met, would greatly improve the quality of life for women with ESRF. First, the State needs to build more dialysis centres to be located around Jeddah so that travelling distances are no longer burdensome for these women. Second, all new medical facilities need to include an annex catering to the special needs of chronically ill women, such as, supervised child-care facilities for young children who have to accompany their mothers and dormitory rooms for women who must stay for long hours waiting for a guardian to drive them home. These amenities would alleviate the anxiety and weariness experienced by these women who always worry about the whereabouts of their children at the dialysis centre, and sit uncomfortably for hours on a bench in a waiting area until they are picked up to go home.

It is crucial to emphasize that the transportation issue comes second in importance after their medical regimen because women are not allowed to drive in Saudi Arabia; and in particular, these women live in the outskirts of the city, far from main roads where taxis are available. Thus, a transportation system that is designed specifically for chronically ill women and provides means to ensure attendance at each and every dialysis session should also be supplied by the State. During transport to the dialysis centre, vehicles must include the appropriate medical equipment accompanied by a nurse to assist them in case an emergency arises. Without adequate and efficient transportation services, these women will continue to miss therapy sessions which can result in further deterioration of their health.

During my interviews (conducted in June 2005), all participants were still waiting for a kidney transplant. Tragically, 22 out of 216 women surveyed are now deceased (as indicated by JKC statistics in January 2008). With the implementation of a national awareness campaign informing the public of the vital need for organ donations, women with ESRF should in future have a better chance to receive a renal transplant.

According to my research findings, Saudi women suffering from ESRF require a great deal of assistance from the State just in order to manage their daily life and maintain a semblance of normality. None of the services cited above can be considered luxury items. All of them are crucial to the basic welfare of these chronically ill women who are still seeking a quality of life that will enable them to function within their family and society. It should be noted that the Eight Development Plan (2005-9) emphasizes the need to improve the quality of life for all Saudi women. However, the specific needs of chronically ill and disabled women are not discussed; and since this five-year developmental plan is still in progress, these policy recommendations should be integrated into the plan. Those programs that can be presently introduced, such as supplemental income and home-health care, should be immediately allocated to these women and their family under an emergency provision.

Reflections

As I review my study, I found that two issues are paramount. The first issue is procedural and the second is circumstantial. The use of the qualitative method in
my study proved to be the most advantageous one for gathering data. After obtaining the data and analyzing it, I found that the most recurrent issue is the participants' lack of economic and social resources. The following is therefore my reflection upon these two considerations.

Procedural considerations

This study is of vital importance because it is the first research that explores Saudi Arabian women's experience with chronic illness. As a Saudi woman who shares a similar cultural background and religious beliefs as the participants, I have a greater awareness of the socio-cultural issues that are particularly sensitive to these women. Furthermore, the fact that the Arabic language in general and Saudi idioms in particular is filled with cultural implications, the true meaning of the participants' narratives would be overlooked by a non-Saudi researcher. As a woman, I was able to establish rapport and visit them in their home environment. A male researcher would never be permitted to interact freely and obtain the necessary insight into the lives of these women that reveal their personal experience with the disease.

My use of the survey was limited to obtaining socio-demographic characteristics for all participants undergoing haemodialysis at JKC (n=216) before systematically selecting a sample of 50 participants for in-depth interviews. Due to the high rate of illiteracy amongst all participants, I had to personally read aloud the survey questions to each of the participants and check their responses. This was more time-consuming than I had anticipated. Since the survey did not allow the participants to expand or clarify their short answers, I decided that the best method for gathering detailed information from the participants was to use in-depth interviews. It was only through the use of this qualitative method of research that I was able to obtain details of their personal experience and meanings in their own words. In this way, they could expand on short answers and clarify vague responses. These women could express their intimate thoughts and feelings without trying to tailor their responses to fit within a structured question and answer format. I was able to identify themes and sub-themes that arose out of their narratives that could have been otherwise overlooked. The only setback I found in conducting in-depth interviews was the time involved. It was difficult to curtail the participants' comments once they felt comfortable in discussing their problems. Their style of speech is typical of Arab expression where a person talks around an issue, rather than getting straight to the point. In addition, since these interviews were conducted within their home, Saudi custom dictates that they act the host and treat me as an honoured guest. This custom prolonged each interview to three or four hours.

I found it necessary to conduct two in-depth interviews with each participant. During the first interview it was important for me to first introduce myself in the dialysis centre and put them at ease with the unfamiliarity of being interviewed by a social researcher. They had previously only been questioned by nurses and doctors about their medical problems, but they had never been asked questions that probed into their everyday life. I also introduced my use of the tape recorder which initially caused them great concern and almost all of them refused to have their first interviews taped.
The second interview took place in the women's home and proved to be the most valuable. Since they were in their own environment, they had more control over the interview process and felt more comfortable with the private setting. It was only during this interview that they were able to relax and trust me enough to agree to being recorded. The second interview also gave the participants another opportunity to explain feelings that they were originally uncomfortable discussing, e.g. their husband having a second wife, and having to leave their home and move in with their legal guardian due to a change in marital status.

Tape recording the interviews proved to be invaluable in that it allowed me to relax and interact with women in a conversational manner, rather than give the appearance of interrogating them. When I was in the privacy of my study, I was then able to review the recordings and make notes regarding their tone and expressions that revealed the underlying meanings of what they were actually saying. In addition, by transcribing the taped narratives, I was able to identify the themes and sub-themes and code them accordingly. It was then necessary for me to translate the transcriptions from Arabic into English after choosing the appropriate excerpts to support the data analysis in my thesis.

After reviewing the data, I realized I could never have gathered detailed information that gave me insight into these women's way of life if I had only conducted a structured survey at the dialysis centre. In fact, I would have obtained a distorted view of their living arrangements and marital relationship if I had restricted my research to data provided in the survey. For example, the survey indicated that some of the participants were married, but these women failed to specifically state that their husband had abandoned them, as I later discovered during the interviews in their home.

**Circumstantial considerations**

The data reveals that the greatest burden on these women aside from their illness is an economic one. It has been established that the Saudi government provides all medical resources but minimal economic support for Saudi women with ESRF, it is their family that bears the brunt of the financial and social burden. Family is actually divided into three branches that share the responsibility for providing the necessary economic resources (income, accommodation and transportation): *al-usrah* [immediate/nuclear family], *al-akarib* [Extended Family] and *al-arham* [In-laws] (Figure 8.2). These three branches do not share this responsibility on an equal basis, but according to the blood relationship, e.g. the father is the closest in blood relation to the participants, however if the father is deceased, the brother is next in line to bear the responsibility of legal guardianship. Yet, there are instances when the legal guardian is unable to provide the necessary economic resources, then another branch of the family network must step in to compensate.

I interpret this process of utilizing alternate family sources of support as a form of checks and balances; but unfortunately it is not effective. This is on account of the family's lack of economic and social resources; the bulk of which are provided by the nuclear family, with only a minuscule amount being provided by the extended family members and in-laws.

The financial burden placed on all branches of the family is extensive because the nature of ESRF is long-term. Since the life-term of the chronically ill individual is
prolonged by dialysis treatment or renal transplant, the immediate family incurs additional expenses over a lifetime. The male legal guardian's economic responsibilities towards a chronically ill and disabled relative extend beyond his limited monthly income. Many of these men are not educated and must accept any odd job that comes along, but job scarcity affects all of them, regardless of education, which is prominent in modern Saudi society where unemployment is widespread. Since there are no unemployment benefits available during these periods of unemployment, the entire family suffers from financial constraints and their economic predicament is never alleviated.

While transcribing the interviews, I found that the lack of economic and social resources was a recurring theme, regardless of the participants' age, marital status or motherhood; and I detected a direct link between the participants' quality of life and their socio-economic status. I could see that the lack of these resources has impacted on every aspect of their life, whether it involves practical matters, such as domestic and non-domestic; or whether it deals with the dynamics of interpersonal relationships. The reason being is that when major responsibility for economic and social resources falls heavily on the family, limitations of support becomes an inevitable constraint on the quality of life for all Saudi women with ESRF.

The quality of life for chronically ill Saudi women is a recurrent theme in this study, as well as the impact of ESRF on the quality of life of their entire family. The participants' life is not the only one that is restricted after the onset of ESRF; the life of each family member who is compelled to care for them is also restricted. For example, the young daughters and sons who consistently miss school and remain home to care for their mothers end up lacking the educational skills to improve their socio-economic status in the future. By forsaking future prospects for the immediate needs of their chronically ill mother, poverty becomes an unending circle that keeps their family in a socio-economic rut. Ironically, the Saudi government spends an enormous amount of money on its special educational and technical programs to combat illiteracy amongst adults; however, children of chronically ill parents are not being educated because there are no caregiving programs to assist the family. This is an illustration of how one medical problem can disrupt and exacerbate the lives of many.

Recommendations for future research

Although the economic issues concerning these participants are pervasive throughout their narratives, it was not the primary topic of my research and therefore was not explicitly an area of investigation. Since the focus of this study is the impact of ESRF on Saudi women and the various aspects of their life, their male guardians were not interviewed. It would be helpful to conduct further research into this area to evaluate the sources of family income, to specifically determine the percentage of income that is actually used for the benefit of these women and to identify how this income is spent. In order to obtain this information, it is important to interview the heads of the household and other male guardians. In addition, it is relevant to interview social welfare agencies to determine how much funds, if any, are made available specifically to women suffering from ESRF. This data will be most valuable in aiding the State to fulfil the Royal Decree 41395 of 29/12/2002 that 'ordered the preparation of a
comprehensive national strategy for poverty alleviation' (MOEP, 2005-9: 191). A specialized survey to assess the needs of these women and design future plans for allocating sufficient funds and programs to low-economic Saudi women with ESRF will establish a database that enables the Saudi Ministry of Economy and Planning and Development to fulfill its responsibilities towards the 'more vulnerable groups of population' (p. 301): chronically ill and disabled women.

It is already known that the long-term nature of ESRF depletes resources of all family members, but since my study is limited to only conducting interviews among women with ESRF, I recommend that future research include interviews with their male and female relatives as well. Since all these relatives assume the responsibility for providing practical support for the participants, this research should determine their social and economic needs that will further enable them to provide this necessary support. In addition, future research needs to closely examine the care-giving role of young daughters who adopt their mother's role by providing domestic care for the entire family, and also act as nurse when caring for their chronically ill mother. The care-giving roles of these young daughters greatly restrict their life and their needs must be identified so that their social and educational requirements are not ignored.

As a researcher and lecturer in the field of sociology, I found no previous research dealing with the impact of chronic illness and disability on Saudis, regardless of gender. Comparative studies examining and identifying the gender-related differences in illness experience need to be undertaken. There is urgent need for future research in these areas of study so that researchers and students can study the impact of chronic illness on the entire Saudi family. Without future sociological research that examines and identifies the needs of chronically ill individuals, as well as the needs of the entire family, policymakers will have no data on which to implement the policy.
References


Kelle, U. (2001) 'Sociological Explanation between Micro and Macro and the Integration of Qualitative and Quantitative Methods', Qualitative Social Research; 2 (1) 45-59.


Ministry of Health (2006), Kingdom of Saudi Arabia: Riyadh. Health Statistical Year Book


Morgan, D. (1998) 'Practice Strategies for Combining Qualitative and Quantitative Methods: Application for Health Research', Qualitative Health Research; 8, 362-76.


Watson, N. (2002) ‘Well, I Know this is Going to Sound Very Strange to you, but I Don’t See Myself as a Disabled Person: Identity and Disability’ *Disability and Society*. 17, (5) 509-29.


APPENDICES
Appendix A
Map of Saudi Arabia
Appendix B
Letter of introduction
(Translated English version)

Dear Interviewee

My name is Eiman Fatani; I am doing a research on the 'Impact of End-Stage Renal Failure on the Everyday Life of Saudi Women.' I am trying to explore how ESRF and haemodialysis affect women's life. I hope that in time my research will lead to better understanding of the dilemmas faced by the chronically ill disabled women. I would like to discuss your experience with the illness.

The interview will take place either at the dialysis centre, your home, or another place of your choice. It will take an hour of your time. The day and time will be arranged a few days in advance to suit you. Everything we discuss will be totally confidential, and only used for the research purpose. Please understand that all names will be coded and only the pseudonym will be used in the reports of this study. No referral made to the patients will be able to associate you with the cases in any way. I also hope you agree for our conversations to be tape recorded.

Thank-you for your cooperation
Eiman M.S. Fatani
تحية طيبة:

أدعى إيمان محمد صالح فطاني، أجرى بحثًا عن "تأثير مرضا الكلى المزمن على المرأة السعودية": أحاول أن اكتشف كيف يؤثر غسيل الدم في أخر مراحل مرضا الكلى على حياة النساء. أمل أن يأتي الوقت الذي يؤدي فيه بحثي إلى فهم أفضل للمتاعب التي تواجه مرضا الكلى المزمن. أود مناقشة تجربتي مع المرضا.

سوف تجري المقابلة إما في المركز أو منزلتك أو مكان آخر حسب اختبارك، وسوف تستغرق حوالي ساعة من وقتك. أي شيء ناقشه سوف يكون في غاية السرية واستخدم فقط لأغراض البحث. كذلك يرجى أن تعلمي أن جميع الأسماء سوف يتم تشفيرها ويستعمل سمي مستعار فقط في التقارير التي تعد بشأن الدراسة. وأي رجوع إلى المرضا لا يمكن أن يتم بموجب ربطك بالحالات المرضا بأي حال.

يرجى قراءة نموذج الموافقة المرفق والتوقع عليه.
Appendix C
Consent Form
(Translated English version)

I have agreed to participate in the research being conducted by Eiman M.S. Fatani, a researcher at the university. I understand that the interview is entirely voluntary, and that I can refuse to answer any questions or stop at any time. I realize that everything I discuss with her will be treated confidentially, and that all this information is strictly for the research purpose. I also understand that all names will be coded and only the pseudonym will be used in the reports of this study, and that no one will be able to associate me with the cases in any way. In addition I also agree for our conversations to be tape recorded.

Participant’s consent [#]
Yes........No..............

Day ........Date..........Time..........Place of interview........

For more information you can call me Eiman M.S. Fatani on phone #........... or Mobile #............

NB. All participants were asked for their consent during the initial interview meeting.
Appendix C(i)
Consent Form
(Arabic version)
نموذج موافقة

واقفون على الاشتراك في البحث بعنوان "تأثير مرض الكلى المزمن على المرأة السعودية" الذي تجريه إيمان محمد صالح فطاني بحثًا اجتماعيًا بالجامعة.

أعلم أن المقابلة طوعيًا تماماً ويمكنني أن أرفض الإجابة عن أي سؤال أو أوقف إجراء المقابلة في أي وقت. تحقق من أن أي شئ أنشأه معها سوف يعالج بسرية وأن جميع هذه المعلومات سوف تكون مقصورة فقط لمرضى البحث ولا توجد أي مخاطر مرتبطة بهذه الدراسة وأن تعانيون طوعيًا تماماً.

كذلك أعلم أن جميع الأسماء سوف تُشفل ويستخدم فقط اسم مستعار في التقارير التي يتم إعدادها بشأن هذه الدراسة، وأنه لا أحد يستطيع أن ينسب إلى هذه الحالات المرضية بأي حال.

كذلك أوافق على تسجيل محادثتنا على شريط تسجيل: نعم – لا

الاسم: .............................................
التوقعي: ................................................

 مواعيد المقابلة الشخصية:
اليوم: .................. 
الوقت: .................. 
المكان: .................. 
التاريخ: ..................

لمزيد من المعلومات يرجى الاتصال ب: 
إيمان محمد صالح فطاني

تليفون: ******

223
I. Female Patient Information:

1. Age: ............

2. Nationality:
   □ Saudi   □ Non-Saudi

3. Place of residence:
   □ Jeddah   □ Jeddah's Vicinity   □ another City

4. How long does it take you to get from your home to King Fahd Hospital’s Kidney Dialysis Centre?
   □ Less than 20 minutes   □ 40-59 minutes   □ Two hours or more
   □ 20-39 minutes   □ One hour or under two hours

5. How do you usually come to the dialysis centre?
   □ By Car/driver   □ Husband’s car   □ Son’s car   □ Friend/Neighbour’s car
   □ Father’s car   □ Brother’s car   □ other relative’s car   □ Taxi/Bus
   □ Varies every time

6. Who do you usually come with for your dialysis sessions?
   □ No one   □ Husband   □ Offspring   □ In-laws   □ Other relative
   □ Friend / Neighbours   □ With a parent   □ Sibling   □ Grand parents
   □ A maid   □ Varies every time

7. Marital status:
   □ Single   □ Married   □ Divorced
   □ Engaged/Milka   □ Separated   □ Widow

8. Number of children: ............

9. Educational level:
   □ Can't read and write   □ Elementary   □ Secondary
   □ Can read and write   □ Intermediate   □ College

10. Employment Status:
    Are you currently employed?
    Yes □   (□ Part-time   □ Full-time)
    No □   (□ I’m retired   □ I’m a homemaker   □ I’m a student)
11. Monthly income (For the patient):
   - No income
   - 1000-1999 SR
   - 2000-2999 SR
   - 3000-3999 SR
   - 500-999 SR
   - Less than 500 SR
   - 1000-1999 SR
   - 5000 SR or more
   - Varies each month

12. Main source of monthly income:
   - Salary
   - Brother/Sister
   - Inheritance
   - Social security
   - Father/Mother
   - Son/Daughter
   - Friends
   - Varies each month
   - Husband
   - Relatives
   - Donations

13. Monthly income (For the head of the household):
   - No income
   - 500-999 SR
   - 2000-2999 SR
   - 1000-1999 SR
   - 3000-3999 SR
   - 4000-4999 SR
   - 5000 SR or more
   - Varies each month
   - Don’t know

14. Accommodation:
   A. Type:
      - Apartment
      - Villa
      - Folk home (Shack)
      - Other
   B. Number of rooms in the house: ..............
   C. Form of payment:
      - Rent
      - Own
      - Donation
      - Other

15. Who lives with you in the same household and how many are there?
   - No one
   - Parents
   - Siblings
   - In-laws
   - Husband
   - Offspring
   - Grandparents
   - Others

II. Diagnosis and dialysis information:

1. When were you first diagnosed with Chronic Renal Disease?
   - Less than 6 months ago
   - 1-3 years
   - 7-9 years
   - 6-11 months
   - 4-6 years
   - 10 or more years

2. Have you ever suffered from any renal problem prior to your dialysis?
   - No, never
   - once
   - several times
   - all the time

3. How long after your diagnosis did you start your first dialysis session?
   - Immediately after the diagnosis
   - 9-11 months
   - Less than 6 months after
   - 1-3 years
   - 6-8 months
   - 4-6 years
   - More than 6 years

4. Where did you have your first dialysis session?
   - Here at King Fahd Hospital
   - At a private facility
   - At another government facility
   - At another city

5. How long have you been on dialysis?
□ Less than 6 months □ 1-3 years □ 10 years or more
□ 6-8 months □ 4-6 years
□ 9-11 months □ 7-9 years

6. How often do you come for dialysis?
□ Three times a week □ once a week
□ Two times a week □ other ...........

7. Have you been evaluated for a Kidney transplant?
□ Yes □ No □ not yet □ not sure
If yes, who do you think would be most likely to donate a Kidney for you?
□ Parents □ Siblings □ Grand parents
□ Spouse □ offspring □ Parents-in-law □ Unknown hospital donor
□ Other □ More than one of these □ not sure □ no-one

III. Medical problems:
1. Indicate which of the following medical conditions do you suffer from?

<table>
<thead>
<tr>
<th>Condition</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hypertension</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Diabetes</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Urinary tract infection (UTI)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Renal stones</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Hereditary renal disease</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
2. Indicate to what extent you experience the following dialysis complications (a) on the days before, and (b) on the same day as your dialysis session?

<table>
<thead>
<tr>
<th>Condition</th>
<th>Not at all</th>
<th>Mild</th>
<th>Moderate</th>
<th>Severe</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dysnia/Chest Pain</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Muscle Cramps</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Headaches</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Nausea/Vomiting</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Back / Body Pain</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Itching</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Fever / Chills</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Weakness</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(a) The <strong>days before</strong> the dialysis session</td>
<td>Not at all</td>
<td>Mild</td>
<td>Moderate</td>
<td>Severe</td>
</tr>
<tr>
<td>(b) The <strong>Same day of</strong> the dialysis session</td>
<td>Not at all</td>
<td>Mild</td>
<td>Moderate</td>
<td>Severe</td>
</tr>
</tbody>
</table>
IV. Psychosocial problems:

1. Indicate to what extent do you experience the following signs (a) on the days before and (b) on the same day as your dialysis session?

<table>
<thead>
<tr>
<th></th>
<th>(a) The days before the dialysis session</th>
<th>(b) The Same day of the dialysis session</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Not at all</td>
<td>Slight</td>
</tr>
<tr>
<td>Agitation</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Anger</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Anxiety</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Depression</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Fatigue</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Fear</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Feeling Despair</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Isolation</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Lack of sleep</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Low self-esteem</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sadness</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

2. Indicate to what extent has any of your (a) physical problems and (b) your psychological problems interfered with your social roles (as a girl/woman, wife, or mother) during the last 6 months?

<table>
<thead>
<tr>
<th></th>
<th>Not at all</th>
<th>Slightly</th>
<th>Moderately</th>
<th>Extremely</th>
</tr>
</thead>
<tbody>
<tr>
<td>(a) Physical problems</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(b) Psychological problems</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

3. Indicate to what extent has any of your (a) physical problems and (b) your psychological problems interfered with your social relationships with your family, friends, neighbours, or others during the last 6 months?

<table>
<thead>
<tr>
<th></th>
<th>Not at all</th>
<th>Slightly</th>
<th>Moderately</th>
<th>Extremely</th>
</tr>
</thead>
<tbody>
<tr>
<td>(a) Physical problems</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(b) Psychological problems</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Appendix D(i)
Survey Questionnaire
(Arabic version)

رقم الحالة:

اليوم:
رقم الوردية:
رقم السرير:
فئة الدم:

1. معلومات عن المريضة:

العمر: 

الجنسية: 
سعودية ☐ غير سعودية ☐

مكان الإقامة:

□ عقيلة □ مدينة أخرى □ ضواحي جدة □ جدة

كم من الوقت يستغرق وصولك من منزلك إلى مركز غسيل الكلى بمستشفى الملك فهد؟ 

□ أقل من 20 دقيقة ☐ 20-39 دقيقة ☐ 40-59 دقيقة ☐ أكثر من 60 دقيقة

5. كيف تأتي عادة إلى المركز لجلسات الغسيل؟

□ بسيرة أخوني □ بسيرة والد □ بسيرة أبلي
□ بسيرة إخوتي/بالحافلة □ بسيرة جرية □ بسيرة قريب
□ بسيرة صديقة/بأمة

6. مع من تأتي عادة إلى المركز لجلسات الغسيل؟

□ لا أحد □ ابن/ابنة □ أخ أو الأخت
□ لأولاد □ الأجداد □ أمه أو الزوج
□ أفراد آخرين □ أفراد أمومة

7. الحالة الاجتماعية:

□ مطلقة □ متزوجة
□ مخطوبة/ملكة □ مزملة

8. عدد الأطفال: 

229
9. المستوى التعليمي:
☐ أمياء
☐ ثانوية
☐ إبتدائية
☐ متوسطة
☐ تعليم عالٍ

10. الوضع الوظيفي:
هل تعملين حالياً:
☐ نعم
☐ لا
☐ عمل جزئي
☐ دوام كامل
☐ أنا متزاعدة
☐ أنا طالبة
☐ أنا مقيعة
☐ أنا ربة منزل
☐ أنا طالبة

11. الدخل الشهري (المريضة):
☐ معدوم الدخل
☐ أقل من 500 ريال سعودي
☐ 500-999 ريال
☐ 3000-3999 ريال
☐ 4000-4999 ريال
☐ 5000 ريال
☐ 5000 ريال أو أكثر
☐ يختلف من شهر إلى آخر

12. المصدر الرئيسي للدخل الشهري:
☐ الراتب
☐ الضرائب
☐ الرى
☐ الأقرباء
☐ الأصدقاء
☐ الورثة
☐ الوالد/والدة
☐ الاصدقاء
☐ الأخ/الأخت
☐ الأقارب

13. الدخل الشهري (رب الأسرة):
☐ معدوم الدخل
☐ لا أعلم
☐ أقل من 500 ريال سعودي
☐ 3000-3999 ريال
☐ 4000-4999 ريال
☐ 5000 ريال
☐ 5000 ريال أو أكثر
☐ يختلف من شهر إلى آخر

14. السكن:
أ. النوع:
☐ شقة
☐ بيت شعبي
☐ أخر
ب. عدد غرف المنزل:
ج. نوع الدفع:
☐ إيجار
☐ ملك
☐ هبة
☐ نوع آخر

15. من يعيش معك في نفس المنزل وكم عددهم؟
☐ لا أحد
☐ أفراد العائلة
☐ الزوج
☐ الأجداد
☐ الوالدان
☐ أهل الزوج
☐ أخرون
☐ الأولاد
التشخيص ومعلومات علاج الفسيل الكاوي:

1. متى كان أول تشخيص لك بمرض الكلي مزمن؟
   □ أقل من 6 شهور مضت □ 6-11 شهر
   □ 4-6 سنة □ 7-9 سنة
   □ 10 سنة أو أكثر

2. هل عانت من قبل الفسيل أي مشكلة بالكلي؟
   □ مرايا لا مطلقا
   □ مرايا

3. كم من الزمن بعد تشخيصك بدأت أول جلسة غسيل؟
   □ فورا بعد التشخيص □ 1-3 سنة
   □ أقل من 6 شهور بعد التشخيص □ 4-6 سنة
   □ أكثر من 6 شهر

4. إن كانت أول جلسة غسيل بالنسبة لك؟
   □ هذا مستشفى الملك فهد □ مستشفى خاص
   □ مستشفى حكومي □ في مدينة أخرى

5. منذ متى وأنت تقومين بعملية الفسيل؟
   □ أقل من 6 شهور □ 4-6 سنة
   □ 6-9 شهور □ 7-9 سنة
   □ 10 سنة أو أكثر □ 11-9 سنة

6. كم مرة تأتي إلى الفسيل؟
   □ مرة واحدة في الأسبوع □ مرة تتبعية في الأسبوع
   □ مرتين في الأسبوع □ أخريات

7. هل تم تقييمك لزراعة كلي؟
   □ نعم □ لا
   □ غير متأكد

إذا كانت الإجابة "نعم" من تعقيد الشخص المحتمل الذي سوف يثير لك بكلية؟

□ الوالدان □ الأب والأخوة □ ألا أحد
□ الزوج □ الأخ/الأخت □ الأب/الأمة
□ ابنة □ أخوة □ متبعري غير معروف من المستشفى
### III. المشاكل الطبية:

1. حدد أي من الحالات الطبية التالية التي تعاني منها؟

<table>
<thead>
<tr>
<th>لا</th>
<th>نعم</th>
</tr>
</thead>
<tbody>
<tr>
<td>ضغط الدم</td>
<td></td>
</tr>
<tr>
<td>التهاب السكري</td>
<td></td>
</tr>
<tr>
<td>التهاب المسالك البولية</td>
<td></td>
</tr>
<tr>
<td>حساسة بالكلية</td>
<td></td>
</tr>
<tr>
<td>مرض كلوي وراثي</td>
<td></td>
</tr>
<tr>
<td>أخرى</td>
<td></td>
</tr>
</tbody>
</table>

2. وضح إلى أي مدى تعاني من مشاكل الغسيل التالية (أ) في اليوم الذي يكون قبل جلسة الغسيل (ب) في نفس يوم جلسة الغسيل؟

<table>
<thead>
<tr>
<th>الأشياء قبل جلسة الغسيل</th>
<th>الأشياء بعد جلسة الغسيل</th>
</tr>
</thead>
<tbody>
<tr>
<td>لا يوجد</td>
<td>شديد</td>
</tr>
<tr>
<td>طفيف</td>
<td>معتدل</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>الأشياء قبل جلسة الغسيل</th>
<th>الأشياء بعد جلسة الغسيل</th>
</tr>
</thead>
<tbody>
<tr>
<td>لا يوجد</td>
<td>شديد</td>
</tr>
<tr>
<td>طفيف</td>
<td>معتدل</td>
</tr>
</tbody>
</table>

### IV. المشاكل النفسية – الاجتماعية:

1. وضح إلى أي درجة تشعر بالآراء التالية (أ) في اليوم الذي يسبق جلسة الغسيل (ب) في نفس يوم جلسة الغسيل.

<table>
<thead>
<tr>
<th>الأشياء قبل جلسة الغسيل</th>
<th>الأشياء بعد جلسة الغسيل</th>
</tr>
</thead>
<tbody>
<tr>
<td>لا يوجد</td>
<td>شديد</td>
</tr>
<tr>
<td>طفيف</td>
<td>معتدل</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>الأشياء قبل جلسة الغسيل</th>
<th>الأشياء بعد جلسة الغسيل</th>
</tr>
</thead>
<tbody>
<tr>
<td>لا يوجد</td>
<td>شديد</td>
</tr>
<tr>
<td>طفيف</td>
<td>معتدل</td>
</tr>
</tbody>
</table>

232
2. وضح إلى أي مدى (أ) مشاكلك البدنية و (ب) مشاكلك النفسية تتدخل مع أدوارك الاجتماعية (كنية/أم، إرادة، أو كام) خلال السنةشهور الماضية؟

<table>
<thead>
<tr>
<th>شديد</th>
<th>معتل</th>
<th>تطيف</th>
<th>طفيف</th>
</tr>
</thead>
<tbody>
<tr>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
</tbody>
</table>

أ. مشاكلك البدنية

ب. مشاكلك النفسية

3. وضح إلى أي مدى (أ) مشاكلك البدنية و (ب) مشاكلك النفسية تتدخل مع علاقاتك الاجتماعية مع أسرتك، صديقتك، جيرانك أو أخرين خلال السنة شهور الماضية؟

<table>
<thead>
<tr>
<th>شديد</th>
<th>معتل</th>
<th>تطيف</th>
<th>طفيف</th>
</tr>
</thead>
<tbody>
<tr>
<td>□</td>
<td>□</td>
<td>□</td>
<td>□</td>
</tr>
</tbody>
</table>

أ. مشاكلك البدنية

ب. مشاكلك النفسية
Appendix E
Interview Guide
(Translated English version)

Introduction:

The purpose of this study is to try to understand the experiences of Saudi women with ESRF; the interviews will give you the opportunity to describe your experience in your own words. You can express yourself freely because there is no 'right' or 'wrong' answer.

I. Demographic Information
*NB: Parts I and II were covered during the first interviews*

- Age
- Marital status
- Number of children
- Employment
- Education
- Income: (source, amount)
- Living arrangements: (number of people living in the same household, relationship to her)
- Transportation: (Who takes you to JKC usually? How long does it take you to get to JKC?)
- Source of support (who)

Type of support: (Household chores, childcare, personal care, escorting, transportation, shopping, etc. prior to ESRD? Who is doing it now?)

II. Medical History:

A. Pre-diagnosis experience:
- Can you tell me how you felt before you decided to visit the doctor?
- Before you visited the doctor, did you take anything or do anything to make yourself feel better?
- What made you decide to visit the doctor?
- How long did you wait to visit the doctor?

B. Diagnosis:
What did the doctor tell you?
- How long did it take to get diagnosed with CRF?
- How did your symptoms change after you were diagnosed with CFR?
- How did you feel and what did you think upon hearing your diagnosis?
- How did your family/friends react when they found out you were suffering from ESRD?

C. Treatment (dialysis):
- How long after your diagnosis did you start dialysis? How long have you been on dialysis?
- What facility did you begin your first sessions?
• How often are your dialysis sessions at JKC?
• Were you evaluated for a kidney transplant?
• Is there a donor? Who?
• Any previous transplant; how long did it last?
• How do you feel? Physically, emotionally?
• How do you manage your illness at home? Monitor your health, diet, medication?

Part III
NB: Part III were covered during the second interviews

A. In what way has ESRF and dialysis affected your life?
   Physically, emotionally, mentally, socially?

   Role (women, wife and/or mother)
   Relationships with family members?

   • Can you describe your daily responsibilities at home and outside the home before your illness?
   • How did you manage these responsibilities after your illness?

B. Is there anything else in your experience that you would like to share with me that I we have not discuss?
Appendix E(i)
Interview Guide
(Arabic version)
دليل المقابلة

المقدمة:
الفشل الكلوي المزمن. سوف تعطيك المقابلة فرصة وصف تجربتك في أسلوبك الخاص. يمكنك أن تعرّي عن نفسك بحرية لأنه لا يوجد إجابة صحيحة أو خاطئة.

1) معلومات دموجرفية:

ملاحظة: الفترات الأولى والثانية سوف يتم تناولها خلال المقابلة الأولى.

- العمر:
- الحالة الاجتماعية:
- عدد الأطفال:
- الوظيفة:
- المستوى التعليمي:
- الدخل: مصدره مقداره
- التنظيم المعيشي:

(عدد الأفراد الذين يعيشون في المنزل وصلة قرابتهم بها)

الموصلات:
- من الذي ينقلك إلى مركز الكلى؟;
- المسافة:
- من المسؤول عن المصدر المساعد:
- ما نوع المسؤول:

(إدارة الأعمال المنزلية، رعاية الأطفال، العناية الشخصية، المراقبة، المواصلات، التسوق)
من الذي يقوم بهذه الأعمال قبل ظهور المرض/وبعده.

2) التاريخ الطبي:

- مرحلة ما قبل التشخيص:

بماذا شعرت قبل اتخاذ قرارك لزيارة الطبيب؟
هل تناولتي أي شي أو قمت بأي عمل شعريتي معه بحسن حالتك قبل زيارتك للطبيب؟
ما الذي نعّل اتخاذ قرار زيارتك للطبيب؟
ما المدة الزمنية التي استغرقتها لزيارة الطبيب؟

- التشخيص:

ماذا أخبرك الطبيب عن حالتك؟
ما المدة التي استغرقته تشخيص الفشل الكلوي المزمن لديك؟
كيف تغيرت الأعراض بعد التشخيص بالفشل الكلوي المزمن لديك؟
ماذا كان شعورك وبعد ذلك كنت تفكرين بعد سماعك لتشخيص حالتاك؟
ماذا كان رد فعل أهلك وأصدقائك عندما علموا بمعاناتك بالفشل الكلوي المزمن؟
العلاج (غسيل الكلى):

- متى بدأت العلاج بالغسيل الكلوي بعد التشخيص؟
- متى كانت أول جلسة للعلاج؟
- ما هي الطريقة المستخدمة غالباً في مركز جدة لغسيل الكلى؟
- هل تم تقييم حالتكم لإجراء زراعة الكلى؟
- هل هناك متبرع؟ من يكون؟
- هل سبق وتم زراعة كلى لك من قبل؟ ومنذ متى؟
- كيف تشعرين عضوياً وجسدياً؟
- كيف تعالجين مرضك في المنزل؟ من حيث المراقبة الصحية والغذائية والعلاجية؟

ملاحظة: لقد تم التغلغل للجزء الثالث من خلال المقابلات الثانية.

- ما مدى كيفية تأثير كلًا من المرحلة النهائية للغسيل الكلوي والمعالجة بالغسيل في حياتك؟
  - من حيث الناحية العضوية والنفسية والعقلية والاجتماعية؟

دور (المرأة: زوجة وأم)

العلاقة مع أفراد الأسرة

- هل بإمكانك شرح مسؤولياتك اليومية في كلا من المنزل وخارجه قبل ظهور المرض؟
- وكيف أستطيعي إدارة هذه المسؤوليات بعد ظهور المرض؟
- هل تودين من خلال تجربتك مشاركتي في أمور أخرى لم تناقش؟
<table>
<thead>
<tr>
<th>Week a</th>
<th>Week a</th>
<th>Week a</th>
<th>Week a</th>
<th>Husband</th>
<th>Brother</th>
<th>Single</th>
<th>Age</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>4 yrs</td>
<td>5 yrs</td>
<td>2 yrs</td>
<td>Husband</td>
<td>6</td>
<td>Married</td>
<td>35</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Personal Characteristics of Women Interviewed**

Appendix F
<table>
<thead>
<tr>
<th>Week</th>
<th>Time at work</th>
<th>House hold</th>
<th>Ever employed</th>
<th>Ever had a child</th>
<th>Ever had a child with the family</th>
<th>First cousin</th>
<th>Ever and/ or divorced</th>
<th>Married</th>
<th>Divorced</th>
<th>Age</th>
</tr>
</thead>
<tbody>
<tr>
<td>First</td>
<td>7 yrs</td>
<td>Household</td>
<td>Never</td>
<td>No</td>
<td>No</td>
<td>First cousin</td>
<td>Never</td>
<td>Married</td>
<td>Divorced</td>
<td>0</td>
</tr>
<tr>
<td>First</td>
<td>5 yrs</td>
<td>Household</td>
<td>Never</td>
<td>Yes</td>
<td>Yes</td>
<td>First cousin</td>
<td>Never</td>
<td>Divorced</td>
<td>Divorced</td>
<td>36</td>
</tr>
<tr>
<td>First</td>
<td>10 yrs</td>
<td>Household</td>
<td>Never</td>
<td>Yes</td>
<td>Yes</td>
<td>First cousin</td>
<td>Never</td>
<td>Divorced</td>
<td>Divorced</td>
<td>27</td>
</tr>
<tr>
<td>Third</td>
<td>7 yrs</td>
<td>Household</td>
<td>Never</td>
<td>Yes</td>
<td>Yes</td>
<td>First cousin</td>
<td>Never</td>
<td>Married</td>
<td>36</td>
<td>36</td>
</tr>
<tr>
<td>Third</td>
<td>10 yrs</td>
<td>Household</td>
<td>Never</td>
<td>Yes</td>
<td>Yes</td>
<td>First cousin</td>
<td>Never</td>
<td>Married</td>
<td>36</td>
<td>36</td>
</tr>
<tr>
<td>Third</td>
<td>2 yrs</td>
<td>Household</td>
<td>Never</td>
<td>No</td>
<td>No</td>
<td>First cousin</td>
<td>Never</td>
<td>Married</td>
<td>6</td>
<td>6</td>
</tr>
<tr>
<td>Third</td>
<td>2 yrs</td>
<td>Personal</td>
<td>Teacher</td>
<td>Never</td>
<td>Never</td>
<td>First cousin</td>
<td>Never</td>
<td>Married</td>
<td>6</td>
<td>6</td>
</tr>
<tr>
<td>Third</td>
<td>2 yrs</td>
<td>Personal</td>
<td>(Government)</td>
<td>Never</td>
<td>Never</td>
<td>First cousin</td>
<td>Never</td>
<td>Married</td>
<td>6</td>
<td>6</td>
</tr>
</tbody>
</table>

Note: The table details the household demographics and employment status of individuals over different time periods, categorized by week and time at work. The data includes whether or not individuals employed, had children, and their marital status.
<table>
<thead>
<tr>
<th>Week a</th>
<th>Number of times a week</th>
<th>Type of Instruction</th>
<th>Who Taught</th>
<th>Years of Instruction</th>
<th>Age of Learner</th>
<th>Gender</th>
<th>Marital Status</th>
<th>Occupation</th>
<th>Education</th>
<th>Last Name</th>
</tr>
</thead>
<tbody>
<tr>
<td>10 yrs</td>
<td>10 yrs</td>
<td>Household</td>
<td>Not employed</td>
<td>Never</td>
<td>Yes</td>
<td>8 children</td>
<td>Son</td>
<td>8 Divorced</td>
<td>39 Hasina</td>
<td></td>
</tr>
<tr>
<td>2 yrs</td>
<td>2 yrs</td>
<td>Household</td>
<td>Not employed</td>
<td>Never</td>
<td>Yes</td>
<td>1 cousin</td>
<td>Husband and son</td>
<td>6 Married</td>
<td>59 Hasina</td>
<td></td>
</tr>
<tr>
<td>4 yrs</td>
<td>4 yrs</td>
<td>Household</td>
<td>Not employed</td>
<td>Elementary</td>
<td>No</td>
<td>4 Parents</td>
<td>Father</td>
<td>1 Failed</td>
<td>25 Chanda</td>
<td></td>
</tr>
<tr>
<td>7 yrs</td>
<td>7 yrs</td>
<td>Household</td>
<td>Not employed</td>
<td>Never</td>
<td>Yes</td>
<td>6 children</td>
<td>Father</td>
<td>Uncle/Grandmother</td>
<td>6 Failed</td>
<td>46 Faluo</td>
</tr>
<tr>
<td>2 yrs</td>
<td>2 yrs</td>
<td>Household</td>
<td>Not employed</td>
<td>Never</td>
<td>Yes</td>
<td>1 Stepson</td>
<td>Husband</td>
<td>Brother</td>
<td>4 Married</td>
<td>27 Faun</td>
</tr>
<tr>
<td>4 yrs</td>
<td>4 yrs</td>
<td>Household</td>
<td>Not employed</td>
<td>Never</td>
<td>Yes</td>
<td>1 stepson</td>
<td>Brother</td>
<td>Married</td>
<td>1 Widowed</td>
<td>40 Fana</td>
</tr>
<tr>
<td>10 yrs</td>
<td>10 yrs</td>
<td>Household</td>
<td>Not employed</td>
<td>Never</td>
<td>Yes</td>
<td>1 Daughter</td>
<td>Husband</td>
<td>Married</td>
<td>0 Widowed</td>
<td>54 Fida</td>
</tr>
<tr>
<td>2 yrs</td>
<td>2 yrs</td>
<td>Personal</td>
<td>Teacher</td>
<td>Retired</td>
<td>No</td>
<td>6 Children</td>
<td>Son</td>
<td>Married</td>
<td>51 Widowed</td>
<td>Dawla</td>
</tr>
<tr>
<td>Week in</td>
<td>Race</td>
<td>Age</td>
<td>Ever Employed</td>
<td>Highest Grade</td>
<td>First Cousin</td>
<td>Family Size</td>
<td>Relationship</td>
<td>Number Married</td>
<td>Employment Status</td>
<td>Income Level</td>
</tr>
<tr>
<td>-----------</td>
<td>------</td>
<td>-----</td>
<td>---------------</td>
<td>---------------</td>
<td>--------------</td>
<td>-------------</td>
<td>--------------</td>
<td>---------------</td>
<td>-----------------</td>
<td>----------------</td>
</tr>
<tr>
<td>1st</td>
<td>7 yrs</td>
<td>Household</td>
<td>Never</td>
<td>Illiterate</td>
<td>No</td>
<td>4</td>
<td>Husband</td>
<td>4 Married</td>
<td>70</td>
<td>English</td>
</tr>
<tr>
<td>2nd</td>
<td>5 yrs</td>
<td>Household</td>
<td>Never</td>
<td>Illiterate</td>
<td>No</td>
<td>4</td>
<td>Husband</td>
<td>4 Married</td>
<td>70</td>
<td>English</td>
</tr>
<tr>
<td>3rd</td>
<td>4 yrs</td>
<td>Household</td>
<td>Never</td>
<td>Illiterate</td>
<td>No</td>
<td>2</td>
<td>Husband</td>
<td>8 Widowed</td>
<td>47</td>
<td>English</td>
</tr>
<tr>
<td>4th</td>
<td>7 yrs</td>
<td>Household</td>
<td>Never</td>
<td>Illiterate</td>
<td>No</td>
<td>6</td>
<td>Husband</td>
<td>6 Married</td>
<td>55</td>
<td>English</td>
</tr>
<tr>
<td>5th</td>
<td>5 yrs</td>
<td>Household</td>
<td>Never</td>
<td>Illiterate</td>
<td>Yes</td>
<td>7</td>
<td>Husband</td>
<td>7 Divorced</td>
<td>26</td>
<td>English</td>
</tr>
<tr>
<td>6th</td>
<td>10 yrs</td>
<td>Household</td>
<td>Never</td>
<td>Illiterate</td>
<td>Yes</td>
<td>7</td>
<td>Husband</td>
<td>7 Married</td>
<td>38</td>
<td>English</td>
</tr>
<tr>
<td>Week of Loss</td>
<td>Days</td>
<td>Household Employment</td>
<td>Highest Level of Education Ever Achieved</td>
<td>First Cousin of Child</td>
<td>Child in Household</td>
<td>Prenatal, Paternal, or Maternal Sibling(s)</td>
<td>Father</td>
<td>Education Level</td>
<td>Race, Ethnicity</td>
<td>Age</td>
</tr>
<tr>
<td>--------------</td>
<td>------</td>
<td>----------------------</td>
<td>-----------------------------------------</td>
<td>----------------------</td>
<td>-------------------</td>
<td>---------------------------------------------</td>
<td>--------</td>
<td>----------------</td>
<td>----------------</td>
<td>-----</td>
</tr>
<tr>
<td>Twice a Week</td>
<td>5 yrs</td>
<td>Household</td>
<td>Married</td>
<td>Never</td>
<td>No</td>
<td>No</td>
<td>Husband</td>
<td>Single</td>
<td>Male</td>
<td>29</td>
</tr>
<tr>
<td>Twice a Week</td>
<td>8 yrs</td>
<td>Household</td>
<td>Married</td>
<td>Never</td>
<td>Yes</td>
<td>No</td>
<td>Husband</td>
<td>Single</td>
<td>Male</td>
<td>49</td>
</tr>
<tr>
<td>Twice a Week</td>
<td>3 yrs</td>
<td>Household</td>
<td>Married</td>
<td>Never</td>
<td>Yes</td>
<td>No</td>
<td>Husband</td>
<td>Single</td>
<td>Male</td>
<td>25</td>
</tr>
<tr>
<td>Twice a Week</td>
<td>2 yrs</td>
<td>Household</td>
<td>Married</td>
<td>Never</td>
<td>Yes</td>
<td>No</td>
<td>Husband</td>
<td>Single</td>
<td>Male</td>
<td>22</td>
</tr>
<tr>
<td>Twice a Week</td>
<td>10 yrs</td>
<td>Household</td>
<td>Married</td>
<td>Never</td>
<td>Yes</td>
<td>No</td>
<td>Husband</td>
<td>Widowed</td>
<td>Male</td>
<td>33</td>
</tr>
<tr>
<td>Once a Year</td>
<td>Less than 1 year</td>
<td>Household</td>
<td>Married</td>
<td>Never</td>
<td>Yes</td>
<td>No</td>
<td>Husband</td>
<td>Widowed</td>
<td>Male</td>
<td>50</td>
</tr>
<tr>
<td>Week used</td>
<td>Age</td>
<td>Marital Status</td>
<td>Employment Status</td>
<td>Education</td>
<td>Living Arrangement</td>
<td>Relationship</td>
<td>Relationship Qualification</td>
<td>Relationship Qualification Qualification</td>
<td></td>
<td></td>
</tr>
<tr>
<td>--------------</td>
<td>-----</td>
<td>----------------</td>
<td>-------------------</td>
<td>------------</td>
<td>--------------------</td>
<td>--------------</td>
<td>--------------------------</td>
<td>-----------------------------------------</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Three weeks a</td>
<td>10 yrs</td>
<td>Married</td>
<td>Never employed</td>
<td>Yes</td>
<td>Household</td>
<td>First cousin</td>
<td>Husband</td>
<td>Step son</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Two weeks a</td>
<td>10 yrs</td>
<td>Single</td>
<td>Never employed</td>
<td>NA</td>
<td>Father</td>
<td>Parent and Step</td>
<td>Granddaughter</td>
<td>N/A</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Three weeks a</td>
<td>7 yrs</td>
<td>Married</td>
<td>Never employed</td>
<td>Yes</td>
<td>Household</td>
<td>Husband</td>
<td>Husband</td>
<td>N/A</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Three weeks a</td>
<td>7 yrs</td>
<td>Single</td>
<td>Never employed</td>
<td>NA</td>
<td>Son</td>
<td>Child and cousin</td>
<td>Husband</td>
<td>N/A</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Three weeks a</td>
<td>3 yrs</td>
<td>Married</td>
<td>Never employed</td>
<td>Yes</td>
<td>Household</td>
<td>First cousin</td>
<td>Husband</td>
<td>N/A</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Three weeks a</td>
<td>5 yrs</td>
<td>Divorced</td>
<td>Never employed</td>
<td>Yes</td>
<td>Uncle</td>
<td>First cousin</td>
<td>Husband</td>
<td>N/A</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Year</td>
<td>Language</td>
<td>Employment</td>
<td>Education</td>
<td>Marital Status</td>
<td>Children</td>
<td>Housing</td>
<td>Age</td>
<td>Gender</td>
<td>Ethnicity</td>
<td></td>
</tr>
<tr>
<td>------</td>
<td>----------</td>
<td>------------</td>
<td>-----------</td>
<td>----------------</td>
<td>----------</td>
<td>---------</td>
<td>-----</td>
<td>--------</td>
<td>-----------</td>
<td></td>
</tr>
<tr>
<td>10 yrs</td>
<td>English</td>
<td>Never employed</td>
<td>Never</td>
<td>Married</td>
<td>No</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>8 yrs</td>
<td>English</td>
<td>Never employed</td>
<td>Intermediate</td>
<td>Married</td>
<td>No</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7 yrs</td>
<td>English</td>
<td>Never employed</td>
<td>Intermediate</td>
<td>Married</td>
<td>No</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Less than a year</td>
<td>English</td>
<td>Never employed</td>
<td>Intermediate</td>
<td>Married</td>
<td>No</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2 yrs</td>
<td>English</td>
<td>Never employed</td>
<td>Secondary</td>
<td>Widowed</td>
<td>1</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4 yrs</td>
<td>English</td>
<td>Employed</td>
<td>Secondary</td>
<td>Single</td>
<td>0</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Week</td>
<td>Lives a</td>
<td>2 yrs</td>
<td>Personal Inheritance</td>
<td>Employed</td>
<td>Illiterate</td>
<td>Child present</td>
<td>Other child present</td>
<td>Living with</td>
<td>Marital Status</td>
<td>Widowed</td>
</tr>
<tr>
<td>------</td>
<td>---------</td>
<td>-------</td>
<td>---------------------</td>
<td>----------</td>
<td>------------</td>
<td>--------------</td>
<td>-------------------</td>
<td>------------</td>
<td>---------------</td>
<td>---------</td>
</tr>
<tr>
<td>1st</td>
<td>Yes</td>
<td>2 yrs</td>
<td>Personal Inheritance</td>
<td>Employed</td>
<td>Illiterate</td>
<td>Yes</td>
<td>No</td>
<td>Husband</td>
<td>Married</td>
<td>5</td>
</tr>
<tr>
<td>1st</td>
<td>Yes</td>
<td>8 yrs</td>
<td>Household</td>
<td>Employed</td>
<td>Illiterate</td>
<td>Yes</td>
<td>No</td>
<td>Husband</td>
<td>Married</td>
<td>4</td>
</tr>
<tr>
<td>2nd</td>
<td>Yes</td>
<td>8 yrs</td>
<td>Household</td>
<td>Employed</td>
<td>Illiterate</td>
<td>No</td>
<td>No</td>
<td>Husband</td>
<td>Married</td>
<td>6</td>
</tr>
<tr>
<td>2nd</td>
<td>Yes</td>
<td>7 yrs</td>
<td>Household</td>
<td>Employed</td>
<td>Illiterate</td>
<td>Yes</td>
<td>No</td>
<td>Husband</td>
<td>Married</td>
<td>7</td>
</tr>
</tbody>
</table>
Appendix G
Glossary

Abaya [the black outer garment required to be worn in public by all Saudi women]
Adhan [call for prayer]
Ahl-al-Khair [benefactors]
Al-aahl [the family]; Aham [my family]
Al-akarib [extended family] from both the paternal and maternal sides; Akaribi [my extended family]
Al-arham [in-laws] representing all relatives by marriage
Al-asdika [friends]
Aldarura laha ahkam [phrase meaning necessity has its laws]
Al-dawlah [State]
Alhamdullilah [thank God]
Al-jeera [neighbours]; Jerani [my neighbours]
Al-kudrah [ability]
Allah [God]
Al-maarif [acquaintances]; Maarifi [my acquaintances]
Almu’min mubtala [true believers are tested through suffering]
Al-ragbah [strong desire]
Al-usrah [the immediate/nuclear family]; Usrati [my immediate family]
Aqikah [baby shower]
Astaghfurallah [God forgive]
Awassi [instruct a verbal will]
Ayats [verses]
Ayamat [orphans]
Ayn [evil eye]
Bint-al-nas [daughter of reputable people]
Dhuhur [afternoon]
Dua’a [supplication]
Gismatn [our destiny]
Gutra [head cover] for men
Hadith [narratives of Prophet Mohammad's life]
Hajj [Pilgrimage]
Hawjati louh mura [phrase meaning, my need for him is bitter]
Ibtilaah min Allah [an infliction from God]
Inshallah [God willing]
Isha’a prayers [late evening]
Khallah [auntie]
Khutab [proposals for wedding]
Maghrib [the early evening]
Mahram [males related to the female by a certain degree of sanguinity/blood relationship]
Makrama [special gift]
Mash’Allah [God protect you] (said to protect the recipient from envy]
Masjids [mosques]
Naseebi inkatab [referring to destiny]
Nama [blessing]
Nikma [curse]
Quran [the revelation of Allah's words]
Ramadan [month of fast]
*Sabr Ayoub* [Prophet Job's patience]
*Salat* [mandatory prayer]
*Sharia'a* [law]
*Sunnah* [practices and teachings of Prophet Mohammad (PBUH)]
*Tarha* [head scarf] for women
*Thobe* [man’s long garment required to be worn in public by all Saudi men]
*Umm* [mother]
*Wallah* [I swear to God]
*Wallahi* [meaning I swear by God]
*Wali-al-amur* [legal guardian]; *Wali-amri* [my legal guardian]
*Zawaj* [marriage]
Appendix H

Abbreviations used

Chronic Renal Failure (CRF)
Chronic Renal Disease (CRD)
End-Stage Renal Failure (ESRF)
End-Stage Renal Disease (ESRD)
Haemodialysis (HD)
Jeddah Kidney Centre (JKC)
Kingdom of Saudi Arabia (KSA)
Ministry of Health (MOH)
Ministry of Economy and Planning (MOEP)
Ministry of Social Affairs (MOSA)
Saudi Centre for Organ Transplantation (SCOT)