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**Oman's treated chronic kidney failure population
in years 1980 to 2015: An epidemiology research**

By

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BSN (USA), MSc (UK)

**Submitted in fulfilment of the requirements for the
Degree of Doctor of Philosophy (PhD)**

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© University of Glasgow**

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Abstract

Background and aim: Epidemiological studies on incidence, prevalence, and other epidemiological variables of Oman's treated kidney failure population have been limited, and questionable as to their use of rigorous research methods. The main aim of this study was to identify the epidemiological variables of treated patients with advanced kidney disease in Oman, the status of publishing on the studied population, and describing the dialysis sub-population characteristics in the northern region of Oman.

Methods: First, a secondary data analysis was performed using data from the Oman's renal replacement therapy (RRT) register (1980-2015). The studied epidemiological variables included: incidence, prevalence, death figures, causes of death and treatment costs of the Oman's treated kidney failure population, especially dialysis sub-population. The publications on chronic kidney failure population of Oman were explored at this stage. Secondly, a multi-centre, cross-sectional study (i.e. survey research) was conducted covering the dialysis sub-population of the northern region of Oman. The basic aim of the survey was to assist in developing the first description of the main characteristics (e.g. demography, primary diagnoses, and co-morbidities) of dialysis-treated patients with advanced kidney disease living the northern region of Oman. A convenience sample ($n = 341$) of participants were recruited from four renal dialysis centres (RDCs). Those who met the pre-specified study inclusion criteria were surveyed using a researcher-administered survey during October and November 2014. SomeFrom December 2014 to December 2015, there were some additional data was gathered (e.g. death figures) from December 2014 to December 2015.

Results: The first RRT care that started in Oman was peritoneal dialysis (PD) in April 1980, while the well-structured PD programme started in 1992 and was boosted in 2007. In 1983, the first dialysis center was opened with seven machines for haemodialysis, serving 35 patients. By the end of 2015, the Ministry of Health (MOH) had 18 RDCs serving 1,439 patients on dialysis per annum for Oman's population. The analysis of the RRT register's data showed that the mean prevalence for all years (1983-2015) was 724.9 dialysis patients per year. The mean incidence for the same years was 203.7 kidney failure patients per year. The mean death rate calculated for all years (1983-2015) was 58 deaths per year. The recorded causes of death were cardiovascular diseases, and infection. Over the years, it was described that death due to infections and cardiovascular diseases were increasing among

the RRT population and particularly within dialysis cohort. The cost of the dialysis sessions increased dramatically from 2,246,627 OMR (~ 4.5 million GBP) in 1998 to 9,543,572 OMR (~20 million GBP) in 2015, which is a 325% increase. Among the databases searched, there were 44 articles, which either focused on, or mentioned Oman's chronic kidney failure population. Most of these articles focused on kidney transplantation and were of limited and questionable methodologies.

In the multi-centre cross-sectional study, the northern region of Oman was divided into two subdivisions. The average age of this population was 51.7 ± 15.8 (mean \pm SD) with no statistical evidence of difference between the subdivisions of the northern region of Oman ($P = 0.177$). There were more males ($n = 187 = 54.8\%$) than females ($n = 154 = 45.2\%$), with no significant difference between subdivisions ($P = 0.598$). It was described that the divorce frequency was low in this population ($n = 22 = 6.4\%$), with no significant difference between subdivisions ($P = 0.49$), but unemployment was high ($n = 292 = 85.9\%$), showing no significant difference between subdivisions ($P = 0.537$). Nearly half of this population were illiterate ($n = 164 = 48.1\%$), with more illiterate females ($n = 103 = 66.9\%$) compared to males ($n = 61 = 32.6\%$), and no significant difference between subdivisions ($P = 0.174$). Nearly half of the participants had been on dialysis for five years at the time of data collection ($n = 165 = 48.4\%$). The most common co-morbidities reported by these participants were hypertension and diabetes combined ($n = 156 = 32.4\%$). The main reported causes of death shown by the data gathered were cardiovascular diseases ($n = 41 = 41.5\%$) and infection ($n = 10 = 10.2\%$). More than half of the participants were hoping to have kidney transplantations as soon as possible ($n = 173 = 50.7\%$).

Conclusion: This study is a comprehensive description of the Oman's RRT epidemiology. The data showed a significant increase in the incidence and prevalence of treated chronic kidney failure in Oman. It showed the increase in the cost of dialysis in Oman for the past 17 years (1998-2015), which is in line with the recent publications from Oman (Al-Alawi et al., 2017; Al-Ismaili et al., 2016) and is in line with global findings. This research's results have contributed to providing a deeper understanding of the Oman's treated chronic kidney failure population. It appears that there is a heavy burden borne by the country, the health sector and the patients on dialysis because of the complex nature of life-long treatment. Oman's publications on this health problem were limited. Therefore, it is necessary to conduct additional research with rigorous methods to obtain a complete picture of this health problem in Oman.

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Preface

To put one self in the shoes of a kidney failure patient is a difficult feeling to live with or tolerate for even a short time. The kidney failure patient, especially on dialysis, has a mixed feeling of pain, anger, and frustration. These patients are due the greatest sympathy. They live their daily life in the trap of their dialysis sessions and their disease complications.

These patients expect death at any time, but some of them still have space for hope. So how can we provide hope for these patients? As I am an academic fellow, I believe hope can come from investment in research. Researchers need to find ways to make spare healthy kidneys available for patients who are eligible for kidney transplantation and for the ineligible patients they need to find alternatives to replace traditional dialysis treatments. The proposed future treatment should offer patients more freedom in life, less pain, and overall a life of better quality and happiness. Also, programs of prevention, screenings, and awareness of kidney disease should be increased among the public and communities as soon as possible. I believe that researchers around the world can collaborate to achieve these goals because the campaign to fight kidney disease is very active at present, especially in the western world.

As a researcher from the eastern part of the world, I believe that my role is to constantly contribute to the body of research regarding kidney disease and other research issues. Therefore I have attempted to critically describe the status of knowledge regarding chronic kidney failure in Oman, and I have found that kidney failure treatments, especially dialysis, drain a significant amount of the health sector budget. The disease is flourishing, but there is no precise data on it, as there is no formal national renal registry at present in Oman. In this thesis, I have tried to gather data on the treated chronic kidney failure population in Oman. It has been a hard journey, full of challenges and mysteries at some points. Research is not an easy task to undertake; it is always a learning opportunity even for experts, and more so for beginners like me.

The flow of this thesis is through eleven chapters. It starts with introduction and literature review, continues with some background about Oman, followed by the methods and materials, the results, the discussions, and finally the conclusion.. The main intention of this thesis is to provide the kidney disease research community with the database necessary

to explore the treated chronic kidney failure population in Oman, and thereafter help to map the route for future kidney disease research. To the best of my knowledge, this is the first step ever under taken in this regard, in this context, I hope the data provided in this thesis are communicated well, to convince policy makers to adopt the recommendations given at the end of this thesis. I hope this thesis is worthwhile and would provide much needed knowledge in this area.

Ruqiya Al-Za'abi

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The idea for this piece of work was born in a memorandum of interest written by myself. However, it was not possible to produce this work without the precious support, love and guidance from those dear to my heart. To the following, I would like to express my extreme gratitude:

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Author's declaration

I declare that, except where explicit reference is made to the contribution of others, this thesis is the result of my own work and has not been submitted for any other degree at the University of Glasgow or any other institution.

Furthermore, the data reported here from the United States Renal Data System (USRDS) or from any other renal registry, the interpretation and reporting of these data are the responsibility of the author and in no way should be seen as an official policy or interpretation of the U.S. government or any other government (unless indicated).

Signature:

Printed Name: RUQIYA KHAMIS AL-ZA'ABI

Abbreviations used in the text

ANZDATA	Australian and New Zealand Dialysis and Transplant Registry
APD	automated peritoneal dialysis
ASN	American Society of Nephrology
AV	arteriovenous
AVF	arteriovenous fistula
AVG	arteriovenous graft
BP	blood pressure
BMI	body mass index
CAPD	continuous ambulatory peritoneal dialysis
CGA	cause, glomerular filtration rate (GFR) category, and albuminuria
CKD	chronic kidney disease
CMS	Medicare & Medicaid Services
CRF	chronic renal failure
CVC	central venous cannula/catheter
CVA	cerebrovascular accident
CVD	cardiovascular disease
DM	diabetes mellitus
DN	diabetic nephropathy
eGFR	estimated glomerular filtration rate
ERA-EDTA	European Renal Association-European Dialysis and Transplant Association
ERF	established (chronic) renal failure
ESKD	end stage kidney disease
ESKF	end stage kidney failure
ESRD	end stage renal disease
ESRF	end stage renal failure
EU	European Union
FVC	femoral venous cannula/catheter
GBP	British Pound
GCC	Gulf Cooperation Countries
GFR	glomerular filtration rate
GN	glomerulonephritis
GNI	Gross National Income
HD	haemodialysis
HRQoL	health related quality of life
HTN	hypertension
IBM SPSS	statistical package for social sciences
IF	Impact Factor
IMRaD	Introduction, Methods and Materials, Results, abstract and Discussion
IQR	interquartile range
J-RBR	Japan Kidney Biopsy Registry
J-KDR	Japan Kidney Disease Registry
KDIGO	Kidney Disease/Improving Global Outcomes
JVC	jugular venous cannula/catheter
KDOQI	Kidney Disease Outcomes Quality Initiative
KDQOL	kidney disease and quality of life
KF	kidney failure
KSA	Kingdom of Saudi Arabia
<i>M</i>	mean
ME	Middle East
Med	median

Max.....	maximum
Mini.....	minimum
mm.....	millimetres
MOH.....	Ministry of Health
MR.....	mortality rate
MRI.....	magnetic resonance imaging
MSSA.....	methicillin sensitive staphylococcus aureus
<i>N</i>	number
NCDs.....	non-communicable diseases
NHS.....	National Health Service
NK.....	not known
NKF.....	National Kidney Foundation
NICE.....	National Institute of Health and Care Excellence
NRLD.....	non-related living donor
NSAIDS.....	non-steroidal anti-inflammatory drugs
OMJ.....	Oman Medical Journal
OMR.....	Omani Rial
<i>P</i>	P-Value
P.cath.....	Permcatheter
PD.....	peritoneal dialysis
PESTLE.....	political, economic, social, technological, legal and environmental
Pmp.....	per million population
PRD.....	primary renal diagnosis
Q1.....	quartile 1
Q2.....	quartile 2
Q & A.....	questions and answers
QoL.....	quality of life
RA.....	Renal Association
RAND.....	research and development
RCTs.....	randomized control trials
RDCs.....	renal dialysis centres
RERAC.....	Research and Ethical Review & Approval Committee in Oman
RRT.....	renal replacement therapy
RT.....	renal transplant
SCOT.....	Saudi Centre for Organ Transplantation
SD.....	standard deviation
SLE.....	systematic lupus erythematosus
SMARRT.....	Scottish mortality audit of renal replacement therapy
SQU.....	Sultan Qaboos University
SQUH.....	Sultan Qaboos University Hospital
SQUML.....	Sultan Qaboos University Medical Library
SRR.....	Scottish Renal Registry
UAE.....	United Arab Emirates
UK.....	United Kingdom
UKRR.....	United Kingdom Renal Registry
UN.....	United Nations
USA.....	United States of America
USRDS.....	The United States Renal Data System
WHO.....	World Health Organisation

Glossary

Arab World: “Arab is a cultural and linguistic term. It refers to those who speak Arabic as their first language. Arabs are united by culture and by history. Arabs are not a race. Some have blue eyes and red hair; others are dark skinned; many are somewhere in between. Most Arabs are Muslims, but there are also millions of Christian Arabs and thousands of Jewish Arabs, just as there are Muslim, Christian, and Jewish Americans. The Arab World consists of 22 countries in the Middle East and North Africa: Algeria, Bahrain, the Comoros Islands, Djibouti, Egypt, Iraq, Jordan, Kuwait, Lebanon, Libya, Morocco, Mauritania, Oman, Palestine, Qatar, Saudi Arabia, Somalia, Sudan, Syria, Tunisia, the United Arab Emirates, and Yemen. Iran and Turkey are not Arab countries, and their primary languages are Farsi and Turkish respectively. Arab countries have a rich diversity of ethnic, linguistic, and religious communities. These include Kurds, Armenians, Berbers and others. There are over 300 million Arabs” (American-Arab Anti-Discrimination Committee, 2009).

BEINGS: “can serve as a mnemonic device for major categories of risk factors for disease, some of which are easier to change or eliminate than other. BEINGS stand for biologic and behavioural factors, environmental factors, immunologic factors, nutritional factors, and services, social, and spiritual factors” (Katz et al, 2014).

ME countries: Middle East countries, composed of 16 countries which are as follows: Egypt, Iran, Turkey, Iraq, Saudi Arabia, Yemen, Syria, UAE, Jordan, Lebanon, Oman, Kuwait, Qatar, Bahrain, and Palestine (Wikipedia the free encyclopaedia, 2017).

SSA countries: Sub-Saharan Countries which include Benin, Botswana, Burkina Faso, Burundi, Cameroon, Cape Verde, Central African Republic, Chad, Comoros, Congo, Cote D’Ivoire, Djibouti, Equatorial Guinea, Eritrea, Ethiopia, Gabon, The Gambia, Ghana, Guinea, Guinea-Bissau, Kenya, Lesotho, Liberia, Madagascar, Malawi, Mali, Mauritania, Mauritius, Mozambique, Namibia, Niger, Nigeria, Reunion, Rwanda, Sao Tome and Principe, Senegal, Seychelles, Sierra Leone, Somalia, South Africa, Sudan, Swaziland, Tanzania, Togo, Uganda, Western Sahara, Zambia and Zimbabwe (The library of Congress, 2010).

List of author's publications and presentations relating to this thesis

Oral presentations and posters:

Al-Za'abi R., Tolmie, E. and Rice, A.M., 2015. End-stage renal disease in the northern region of Oman: epidemiology, incidence and aetiology. *The Omani Open Day Conference* - organised by Omani Students' Advisory Council (UK) Scientific Committee and the Embassy of Oman in London: Poster display and presentation with Q & A session. The poster achieved fourth top poster on 31st January 2015, Loughborough, UK.

Al-Za'abi R., Tolmie, E. and Rice, A.M., 2015. Renal failure in the northern region of Oman: epidemiology, incidence and mortality rate (methodological approach). *The 15th European Doctoral Conference in Nursing Science (EDCNS 2015)*, organised by the Medical University of Graz. Oral presentation (Session 5) for 15 minutes, followed by Q & A session for five minutes, and facilitated by an expert in research methodology (Prof. S.Hahn). 18th-19th September 2015. Graz, Austria.

Al-Za'abi R., Tolmie, E., Rice AM., Mohsin N. and Al-Busaidi, A., 2016. Epidemiology, incidence and mortality rate of renal failure patients in the northern region of Oman: Cross-sectional study results. *The RCN (Research Conference in Nursing 2016)*, abstract number 111 session 3.3.1 under mixed methods sessions) presentation for 15 minutes, followed by Q & A for five minutes. 6th-8th April 2016. Edinburgh, UK.

Al-Za'abi R., Tolmie, E., Rice AM., Mohsin N. and Al-Busaidi, A., 2016. The growing prevalence and cost of maintenance dialysis treatment in Oman: Review of statistical figures from 1983 until 2013: a retrospective review. *The European Kidney Association - European Dialysis and Transplant Association (ERA-EDTA 2016)*. Poster session (poster number MP621) in the poster area with Q & A session from 9:30-10:45. 21st-24th May 2016, Vienna, Austria.

Al-Za'abi R., Tolmie, E., Rice AM., Mohsin N. and Al-Busaidi, A., 2016. The growing prevalence and cost of maintenance dialysis treatment in Oman: a retrospective

observational cohort from 1983 until 2013. *The 16th European Doctoral Conference in Nursing Science (EDCNS 2016)*, organised by the Bern University of Applied Sciences-Health. Oral presentation (Session 9) for 15 minutes followed by Q & A session for five minutes (Bern, Switzerland, 16th-17th September 2016).

Publications:

Al-Za'abi R., Tolmie, E., Rice AM., Mohsin N. and Al-Busaidi, A., 2015. Abstract published in the American Society of Nephrology (ASN's 2015), Abstract Supplement of *JASN* (Abstract Number, PUB347 on page 968A) as well as included in the Kidney Week 2015 Program Builder, both of which were available via the ASN website by 2nd October 2015, and remained online for one year.

Al-Za'abi R., Tolmie, E., Rice AM., Mohsin N. and Al-Busaidi, A., 2015. Abstract published in the scientific newsletter (called *Nitaj*) for Omani research students in the UK (sponsored by the Omani Students' Advisory Council (UK) - Scientific Committee and Embassy of Oman in London), published in November 2015 (Volume 1, Issue No.1, page 62). It was a rich experience to be one of the editorial board's members of this newsletter.

Al-Za'abi R., Tolmie, E., Rice AM., Mohsin N. and Al-Busaidi, A., 2016. Abstract published in the scientific newsletter (*Nitaj*) for Omani research students in the UK (sponsored by the Omani Students' Advisory Council (UK) - Scientific Committee and Embassy of Oman in London), published in November 2016 (Volume 2, Issue No.1).

Prizes:

Second best study project by Omani students studying in the UK (2016).

1.1 Introduction

1.2 Overview

Worldwide, the rates and burden of chronic diseases or non-communicable diseases (NCDs) are rising due to the ageing population and the increased prevalence of diabetes, hypertension and obesity (Farag et al., 2012; Thomas et al., 2015; Hill et al., 2016). Out of 57 million deaths worldwide, 63% were due to NCDs in 2008 and increased to 65% in 2010 (Perico and Remuzzi, 2012; Lozano et al., 2013). As a result, the United Nations (UN) initiated a programme to reduce the premature mortality secondary to NCDs by 25% by 2025 (World Health Organisation – WHO, 2014; United Nations – UN, 2014).

Kidney failure is a chronic disease that is not yet included in the UN initiative, but diabetes, which is a major cause of kidney failure is included. Also chronic kidney disease is becoming a health priority in many agendas of health care systems across the world. The global evidence shows the increasing incidence and prevalence of treated kidney failure patients, who need kidney dialysis or kidney transplantation, with poor outcomes, increased cost and increased health burden (Couser et al., 2011; Hill et al., 2016). In the UK, around three million people have kidney disease, 60 thousand people die prematurely because of chronic kidney disease every year, and there are 64 thousand people with kidney failure undergoing treatment (Kidney Research UK, 2013). Worldwide, maintenance dialysis treatment has dramatically increased 1.7 times from 165 per million population (pmp) in 1990 to 284 pmp in 2010 (Thomas et al., 2015). Although patients who need dialysis or transplantation are only 1-2% of the Chronic Kidney Disease (CKD) population, the cost for this 1-2% is considerably high, where it can reach 5% of the annual budgets of national health services (Kidney Disease/Improving Global Outcomes – KDIGO, 2013; National Institute for Health and Care Excellence – NICE, 2015). In the USA, the cost of treating kidney failure increased from \$30.4 billion (£23.4 billion) in 2012 to \$30.9 billion (£23.8 billion) in 2013 and accounted for 7.1% of total Medicare spending (National Institute of Diabetes and Digestive and Kidney Diseases, 2016). In Saudi Arabia, the annual cost was 800 million Saudi Rials (£162 million) per year for 14,562 treated kidney failure patients in 2012 (Saudi Center for Organ Transplantation – SCOT, 2013).

Chronic kidney failure is a life-threatening disease where the majority of patients have to undergo dialysis treatment for the rest of their lives. Dialysis treatment is associated with

high rates of mortality and morbidity, with patients frequently experiencing infection and hospitalisation (Lafrance et al., 2014). For example, treated patients with advanced kidney disease in the USA experienced hospitalisation twice a year on average, and an average of one unplanned rehospitalization for about 30% of this population within the 30 days following their discharge (United States Renal Data System – USRDS, 2015). In the UK renal dialysis population, the Methicillin Sensitive Staphylococcus Aureus (MSSA) bacteraemia infection reached a rate of 1.59 per 100 dialysis patient from 1st May 2012 to 30th April 2013 which leads to patients’ hospitalisation (United Kingdom Renal Registry-UKRR, 2014).

Mortality rates in dialysis populations are ten times higher compared with people of a similar age without kidney disease (United States Renal Data System – USRDS, 2013). For example, three years after starting dialysis in 2006, only 52% of haemodialysis patients and 61% of peritoneal dialysis patients remained alive in the USA (United States Renal Data System – USRDS, 2013). Also, the patient with chronic kidney failure has to cope with many major stressors in their lives, including first their diagnosis with kidney failure and ending with symptoms like itching and lack of energy, limited food and fluid intake, and psychosocial stressors such as impaired self-esteem and feeling uncertain about the future (Murphy, 2014).

Also, renal care providers experience major stressors while treating CKD and especially while treating dialysis patients as these patients undergo prolonged dialysis treatments. Renal care providers continuously try to improve survival rates and the quality of this treatment, or attempt to improve the dialysis outcomes by, for example, increasing dialysis frequency and duration which at the end lead to increasing their load of work (Kidney Disease/Improving Global Outcomes – KDIGO, 2015). The advancement in kidney failure care management and technologies (especially dialysis), the increasing prevalence of kidney failure leading to increasing workload, and the complexity of caring for such a demanding condition, place a greater burden (i.e. physical and emotional) on renal nurses particularly, because nurses have more contact with these patients on a daily basis compared to other renal care providers, such as nephrologists, nutritionists, psychologists, and social workers (Thomas, 2014, p.xi). Renal nurses and other renal care providers have to keep up-to-date with new technologies of kidney failure treatment, with the best guidelines and management strategies for kidney failure patients, with the latest epidemiological profiles, and with the best evidence-based practices in renal care to

provide optimal care for their patients (Thomas, 2014, p.xi). Renal nurses especially have to adapt to an increasing workload as a result of the increasing prevalence and incidence of kidney failure globally. In general, renal care providers and renal nurses particularly are challenged on a daily basis by the physical and psychosocial needs (e.g. some patients face depression, anxiety and poor coping mechanisms) of their kidney failure patients and their patients' families (Thomas, 2014, p.xi).

In some parts of the world, for example Europe, there is an extensive database on some aspects of kidney failure, such as the epidemiology, and the characteristics of the treated kidney failure population in Europe. These data are collected and archived by the renal registry called the European Kidney Association - European Dialysis and Transplant Association (ERA-EDTA) and published on an annual basis. The ERA-EDTA is a pioneer in retrieving data for kidney diseases and kidney failure from 1964 until the present (Davids et al., 2016). On the other hand, there are parts of the world that do not have a well-formed renal data resource or specialised renal data source for kidney failure population. For example China, which has around 20% of the world's population, does not have a national renal registry yet, but it does have Chinese Society of Nephrology which cover a broader spectrum of renal aspects (Yao et al., 2009; Liu, 2015). So this imbalance in data availability and data production between the west and the east parts of the world make the picture of chronic kidney failure incomplete. It is determined that the eastern part of the world, which includes the developing countries such as the Middle East (ME) and Arab world (see Glossary, p.18), has to work harder to provide the world with accurate statistics and findings for chronic kidney failure. Access to this information will help the world first to assess the real situation regarding kidney diseases across the board, and then to plan ahead to prevent deeper and more complicated outcomes of this critical disease globally.

1.3 Kidney failure

Kidney failure and renal replacement therapy (RRT) are the key concepts of this project. The only treatment for kidney failure is RRT, which means kidney transplantation or dialysis, and if not, then a conservative treatment should be followed by patient. The data available on the use of conservative treatment is limited (Chandna et al., 2010; Teruel et al., 2015). A study by Teruel et al., 2015, assessed the frequency of conservative treatment among chronic kidney failure patient from 1st July 2013 to 30th June 2014, and found that,

out of 232 patients with kidney failure, about 39% received conservative therapy. The major factors associated with selecting conservative therapy were age, co-morbidity, and functional disability. Another single-centre cohort study conducted in the UK (Carson et al., 2009) concluded that patients (n=29 = 14%, chose conservative therapy from the 202 elderly patients involved) who follow maximum conservative therapy, can achieve a similar number of hospital-free days and can survive a considerable length of time comparable to haemodialysis patients. The generalizability of the evidence from these two studies is limited due to their small sample size and the unavailability of further evidence to compare with. This area is generally underexplored.

Kidney transplantation as the optimal treatment for kidney failure is faced with major challenges, such as shortage of kidney donors and religious or cultural beliefs, which restrain the process of kidney donation. In the UK there are no major objections to organ donation and transplantation from religious groups (Dunsmore, 2014). However, there are groups such as the Jehovah's Witnesses who allow organ donation and transplantation only if Jehovah's Witnesses religious leadership approve it (Dunsmore, 2014). For a long time, Muslims have thought that organ donation was not allowed in Islam. However, the fatwa (i.e. decision) from the Muslim Law Council allows for organ donations and transplantations as long as the process causes no harm to either donor or recipient (Dunsmore, 2014). However, the concept of "doing good while doing no harm" still encompasses an ethical dilemma for some stakeholders around the world and can cause delay or objection to organ donation (Beauchamp and Childress, 2013; Dunsmore, 2014).

Dialysis is the second sub-optimal treatment for kidney failure. This treatment has its own areas of controversy. There is an on-going debate on whether convective dialysis (see Glossary, p.18) is preferred over traditional haemodialysis (Nistor et al., 2015). This evidence was evaluated by two reviews conducted by the Cochrane Collaboration and published in the Cochrane Library. The first Cochrane review was conducted in 2006, and after reviewing 20 studies, including 667 patients, the review found insufficient evidence supporting convective dialysis over traditional haemodialysis (Rabindranath et al., 2006). The second systematic review was in 2015 and included 40 studies with 3,483 patients. It concluded that convective dialysis may reduce cardiovascular mortality, but the evidence produced by the included studies was not reliable due to serious limitations in study methodologies. Therefore, this area still needs further scientific testing and reliable

assessment to prove that convection dialysis can give better outcomes over traditional haemodialysis (Nistor et al., 2015).

The patient on haemodialysis has to regularly undergo at least four hours of haemodialysis three times a week (Murphy, 2014; Kidney Disease/Improving Global Outcomes – KDIGO, 2015). It is quite impossible for a dialysis machine to achieve similar results to that of a normal kidney within twelve hours of dialysis per week (i.e. dialysis dose); this regimen, in fact, provides less than 10% efficiency compared to normal functioning kidneys (Zhu et al., 2012). This could be the main reason behind the high rates of mortality and morbidity among dialysis patients across the world compared to the normal population. Even if compared with a kidney transplant, the dialysis patient's mortality rate is five times higher (Zhu et al., 2012; United States Renal Data System – USRDS, 2015).

In general, patients on dialysis can choose between home or in-centre haemodialysis. However, an on-going debate suggests that there are some described benefits of home haemodialysis over in-centre haemodialysis, such as high survival rate, less hospitalisation frequency and overall better quality of life (Palmer et al., 2014). The evidence supporting home dialysis over in-centre dialysis is limited as evidenced by the following systematic reviews. A Cochrane review reported that there were numerous observational studies on home haemodialysis, which showed that the described patients had a better quality of life and improved survival rate (Palmer et al., 2014). The same review, found there was only one randomised control trial (RCT) testing the same aspect and it included only nine patients, which implies the limited generalizability of this study's results (Palmer et al., 2014). In general, the randomisation feature and the comparison between the treatment cohort and the control cohort may reduce the research methodological defects such as having younger or fewer health problems in one of the cohorts. Also, the pre-specified outcomes that are measured by any RCT allow for more objective comparison and more reliable analysis. This suggests that the evidence available for home dialysis is not yet reliable until more randomised control trials are conducted to measure the benefits of adequate home haemodialysis over the traditional in-centre haemodialysis (Palmer et al., 2014).

Regular and prolonged haemodialysis requires long-term vascular access. The ideal choices are arteriovenous fistulae (AVF) and arteriovenous grafts (AVG). The least favoured option is central venous catheters (CVC) because CVC are at high risk of

complications such as bleeding and infection (Fluck and Kumwenda, 2011). Arteriovenous fistulae and arteriovenous grafts are recommended for patients on haemodialysis because of their better outcomes, such as long-term patency, improved flow rates and fewer described complications (Challinor, 2014). However, vascular access creation needs early planning and preparation, and needs an expert surgical team to handle the procedure (Murphy, 2011). The standard procedure is to plan for vascular access creation when the patient reaches CKD stage four (usually 3-4 months before initiating dialysis), so that access will be ready by the time the patient needs haemodialysis (Fluck and Kumwenda, 2011).

Peritoneal dialysis is less costly than haemodialysis because it does not require expensive equipment, machines and specialised staff and technicians to handle the procedure (Karopadi et al., 2013). One of the major challenges of peritoneal dialysis is the need for an individualised treatment plan that considers the clinical and lifestyle needs of each patient, such as the appropriate peritoneal dialysis modality and dose, and the special diets the patient must follow. There is an agreement across the literature on the cost-effectiveness of peritoneal dialysis compared to haemodialysis, but despite the vast studies investigating the cost effectiveness of peritoneal dialysis, the systematic reviews on this aspect are rare (Main, 2014). Only two systematic reviews weighing the evidence on peritoneal dialysis cost effectiveness were identified by author. First one is a bit of old date which is Cochrane systematic review conducted by Vale et al. (2004) concluded that there is insufficient data coming from robust RCTs and well-designed observational studies on comparing the effectiveness of peritoneal dialysis (CAPD or APD – see Glossary, p.18) to the different haemodialysis modalities (Vale et al., 2004). The second systematic review and meta-analysis study included 13 publications up to August 2013, from Europe, the USA, Asia and Canada, concluded that over a five-year horizon, peritoneal dialysis is significantly more cost effective compared to haemodialysis treatment (Pike et al., 2017). However this conclusion was based on studies that had high risk of bias and their evidences appraised as low to very low quality which indicate that the evidence supporting the cost effectiveness of peritoneal dialysis is yet need further investigations and support.

There is sufficient literature reporting the primary causes of kidney failure as respectively, diabetes, hypertension and vascular diseases, and risk factors such as gender, ethnicity and obesity. Also, the cause of kidney failure in many instances was reported as ‘unknown’. This area of understanding the cause-and-effect relationship is complex for all diseases,

and kidney failure is no exception. However, the evidence available on the increasing epidemic of this serious disease, on the high cost and hardship of kidney failure treatments, and on the high mortality rates, all add urgency to study this disease further from its all aspects.

1.4 Conclusion

The previous two sections (i.e. 1.1 and 1.2) were helpful in understanding the topic of kidney failure, its treatments and its significance as an irreversible chronic disease that affects many people across the world. However, further review of the literature was needed to explore the epidemiology of renal replacement therapy in Oman, and of the international picture, and also to explore the international state of the quality of life of people with advanced kidney disease. Also, the literature review helps to identify the major data sources of treated people with advanced kidney disease, like renal registries and helps to identify potential areas for research and similar research studies that have been conducted. Therefore, the following chapter is dedicated to exploring these concepts.

2 Published reports used to obtain data on the epidemiology of RRT

2.1 Published reports used to obtain data on the epidemiology of RRT of Oman

2.1.1 Search strategy (initial stage)

This task accomplished in late 2013 and early 2014 via searching different databases such as EBSCOhost, Ovid MEDLINE, Web of Science, PubMed, Medscape, and University of Sultan Qaboos Library Website (Oman database). There were few studies matching the inclusion criteria that found in Ovid MEDLINE, Web of Science, PubMed, Medscape, and University of Sultan Qaboos Library Website. The inclusion criteria were mainly; the subject has to have kidney failure; the context should be Oman; and the scope is epidemiology. The exclusions were any articles that did not fit with the inclusion criteria or were duplicated. There was no single article identified on the epidemiology of kidney failure while searching Sultan Qaboos Library. On the other hand, the most retrieved articles were identified by EBSCOhost search engine accessed via the University of Glasgow library link. Therefore EBSCOhost searched strategy will be described here in some detail. First of all, the search terminologies used were “nephrology in Oman”; “renal failure in Oman”; “ESRD in Oman”; “Nephrology AND in Oman”; “ESRD AND Oman”; “kidney failure AND in Oman”; the larger volume of retrieved studies were gathered by using the search term “renal or kidney failure AND Oman”. The words epidemiology, incidence or prevalence was not added to the search terminologies at this stage to avoid narrowing down the search and therefore avoid missing any study that mentioned kidney failure in Oman, but failed to include epidemiology, incidence or prevalence terms putting in mind that retrieved articles will be screened for eligibility later on. The search options selected were all the ones on the default search screen of EBSCOhost without restrictions except “published date” was limited from January 1980 to December 2013 because nephrology started in Oman in 1980s. The first dated study paper the search engine was able to find was for the year 1988. Also the search was limited to English language only because English is the main medium of publishing health subject articles in Oman. The search engine picked 145 studies; after screening only two studies mention Oman’s kidney

failure epidemiology (Figure 2-1). Also one more study was found by using Google scholar search.

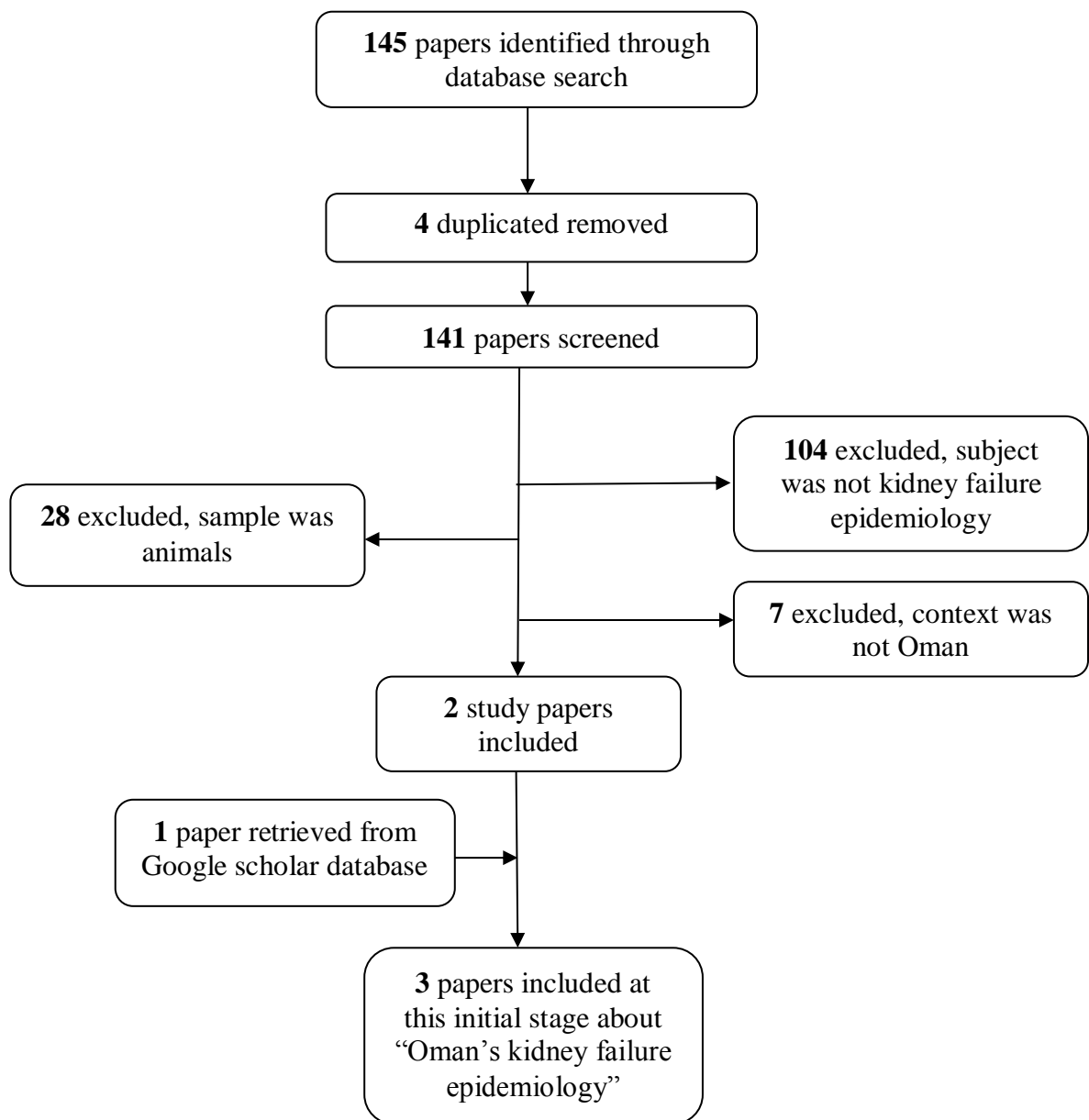


Figure 2-1 Flow diagram for selection of studies

After reviewing these reports, there were only three articles (i.e. Al-Marhuby, 1998; Abboud, 2006; Hassanien et al., 2012) which have focussed on the Oman's treated kidney failure epidemiological data. At this point, the conclusion was that the published knowledge coming from Oman about kidney failure was limited. Also this conclusion was confirmed by Dr.Omar Abboud, the author of the above mentioned 2006 article (see appendix B-5 on p. 251). However, this conclusion was handled with caution because at this stage the grey literature of Oman (e.g. unpublished MOH reports or studies) was not

accessible to the author. The author has to be physically present in Oman to get access to the unpublished data and sometimes the national published data. Access can be obtained only after getting the ethical approval from the MOH of Oman. Therefore there was intensive hand and online search conducted later in 2014 for the grey literature while the author was in Oman and also a follow-up online search while back to the University of Glasgow. As all the intensive literature searching was conducted in 2014, the search deadline was always limited to the end of 2013.

2.1.2 The search strategy (intensive stage)

The published and unpublished reports used to obtain data on the epidemiology of RRT of Oman was mostly gathered by this search method. This search was conducted during the data collection stage, however, it is detailed here so all literature review on this aspect is compiled together in one section to avoid confusion. This stage was launched by getting the ethical approval letter of Oman's MOH so access to published and unpublished materials is gained. The ethical approval letter was handed to the nephrologist in charge of the central RDC in the capital of Oman and the heads of the other four RDCs (i.e. data collection locations) in the northern region of Oman. The requested data were any publications on Oman's kidney failure epidemiology. Only one single study was retrieved from the nephrologist in charge of the central RDC (i.e. WHO study (EMRO SPLT GRANT – TSA 03/23) – research proposal on “frequency of diagnosed hypertension, proteinuria, haematuria, urinary tract infection impaired kidney function and their geographical distribution amongst different age group of individuals in Sultanate of Oman.” This study was published on the national level of Oman and its subject is not entirely on kidney failure epidemiology.

Moreover another step was taken to find more grey literature on Oman's kidney failure epidemiology. The author visited the medical library of the Sultan Qaboos University in the capital and inspected the national and local publications and records relevant to the subject Oman's kidney failure, by doing hand search through the Oman Medical Journal (OMJ), the main scientific journal publishing medical and healthcare research in Oman. All the OMJ issues (found available in the SQU-medical library) were searched by hand and there were 15 potential reports retrieved. Thereafter, all the relevant reports found related to kidney failure in Oman were extracted, copied and compiled for further

screening and reviewing (i.e. 15 reports – sample of these reports are under appendix E-2, p.267). One additional report was referred to by a colleague, and its abstract was successfully retrieved by the SQU librarian and sent to the author. Also, the annual health records of the MOH of Oman were manually inspected when they were not available electronically. This annual record was very helpful in tracking the prevalence of dialysis patients since 1998 (first published annual report found by the author) until 2015 (the last published record until the last point of inspection of this research– sample of the section relevant to kidney dialysis in the MOH health annual report is under appendix E-1, p.266).

Further online searching followed this stage and this time with a librarian consultation. As a result considerable numbers of publications, which potentially covered Oman's kidney failure subject, were gathered via the online search facility of the University of Glasgow Library. Hence this search was critical and vital for this study; the search strategy is illustrated in the following.

After some consultations with the librarian of the UoG (nursing school), it was suggested that searching the databases of MEDLINE, Web of Science, and Cochrane library might give similar or even less search results to an Ovid Embase search and that was the conclusion arrived after some trials on searching these databases. The OVID Embase was more comprehensive and gave more results even when compared to EBSCOhost database. Therefore the OVID Embase search strategy is illustrated here in some details.

The OVID Embase '1947-present, updated daily' option was selected. The search terminologies were classified as themes to ensure the best filtration process for the required articles. The major themes and terminologies are illustrated in Table 2-1. The terminologies under the three themes were searched separately, then the similar themes' terminologies were combined using OR, and lastly the three different themes search were combined using AND. Some search limitations were added such as a date limit from January 1980 to December 2013 because nephrology started in Oman in 1980 and the study search target deadline was the end of 2013. Also, the search was limited to English language only because it is the main medium for publishing health topics in the scientific journals in Oman. After all searches had been completed on OVID Embase, 1000 articles were identified.

Table 2-1 The main themes and terminologies used to search OVID Embase database

Theme One: Population (terms)	Theme Two: Intervention (terms)	Theme Three: Condition (terms)
(Oman or Gulf Cooperative Country or GCC or Arab*) adj2 (World or countr*) or Middle East Countr* or (developing or underdevelop*) or Sahel or Third World Countr*	(kidney or renal) adj2 (dialysis or support or hemodial*) adj2 (therap* or treatment) (kidney or renal) adj2 (transplant* or replacement) adj2 (therap* or treatment)	(end or terminal or final or chronic) adj2 (kidney or renal) adj2 (disease* or failure or dysfunction or impairment or insufficien*)

The articles identified from other databases like EBSCOhost were 257 articles. Also, the Cochrane library by subject (kidney) was searched, and 38 articles and reviews were identified. Also, Enlighten of University of Glasgow, was searched to retrieve theses, and there were 33 potential relevant theses, however after scrutinizing these 33 theses, none were found relevant to this study. ProQuest database was searched, and there were 321 theses were identified, but after scrutinizing none of them were about the epidemiology of kidney failure in Oman (Figure 2-2). Noticeably, on ProQuest database, there were two theses identified for Oman, but neither of them was about kidney failure or RRT; one thesis focused on cardiomyopathy (2006), and the other were about diabetes self-management (2013).

As a result, there were 1666 potentially relevant references. These were initially retrieved from all searched databases and sources (Figure 2-2). At the end of this phase, there were 44 articles identified as relevant (Figure 2-2).

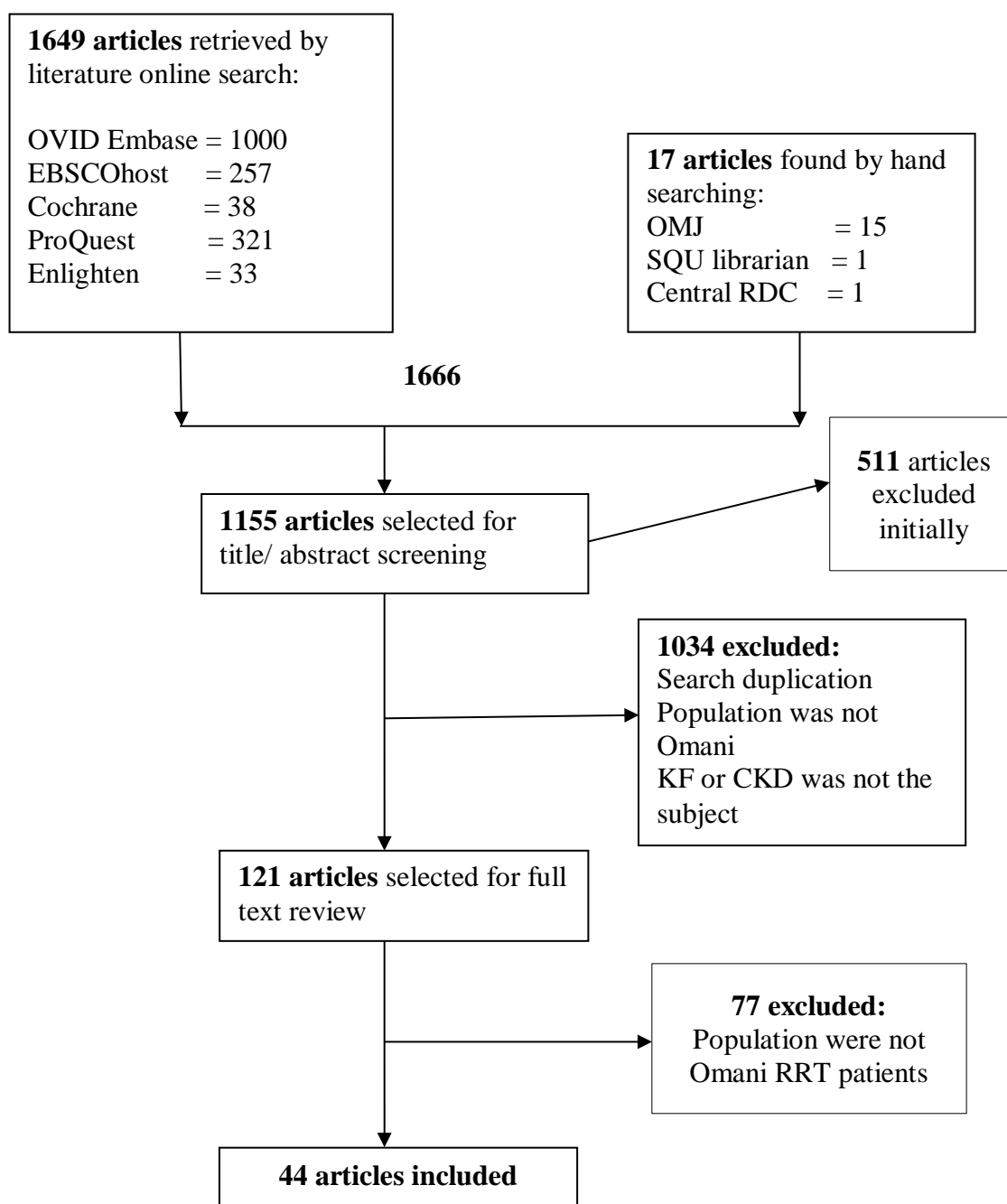


Figure 2-2 Filtration process of literature of kidney failure or RRT in Oman

Among the databases searched, there were 44 articles published until the end of 2013, which focused on or mentioned Oman's RRT population. However, the epidemiology of kidney failure was the full focus of two studies (4.5%) only (Woods and Prabhakar, 1985; Al-Marhuby, 1998 – see appendix F, p.269) which are both older studies. There were five (11.4%) other studies which mentioned epidemiology of kidney diseases in Oman briefly (Al-Dhahry et al., 1993; Al-Dhahry et al., 1994; Abboud, 2006; Alashek et al., 2012; Hassanein et al., 2012). Kidney transplantation was the most popular researched topic for

RRT population of Oman, as more than one third of the included studies ($n = 16$ studies = 36.4%) were handling this topic. The remaining articles ($n = 21 = 47.7%$) were either exploring the risk factors of CKD or discussing general topics related to RRT population in Oman. The most popular research design used were cross sectional ($n = 14 = 31.8%$), followed by observational cohorts ($n = 8 = 18.1%$), and case reports ($n = 8 = 18.1%$ - see appendix F, p.269).

2.1.3 The conclusions from the published reports on Oman's RRT up to 2013

Oman is one of these developing countries which need to escalate efforts in kidney failure epidemiology (Hassanien et al., 2012). Access to the epidemiology of chronic kidney failure in Oman is very limited for the world beyond Oman, because there has been no sufficient publication covering this matter until this project was undertaken in 2013. One report with older date (Al-Marhuby, 1998) had reported brief and limited information about RRT in Oman such as incidence, prevalence, causes of death and brief history of kidney transplantation in Oman. A systematic review published in 2012 reviewed the epidemiology of chronic kidney failure in the Gulf Cooperation Council (GCC, i.e. Oman, UAE, Saudi Arabia, Kuwait, Bahrain and Qatar), and showed that the incidence of chronic kidney failure has increased, whereas the prevalence and mortality rate has not been reported sufficiently (Hassanien et al., 2012). Hassanien et al. (2012) stated that there were no studies from either Oman or Qatar. The review recommended conducting more studies to describe the epidemiology of chronic kidney failure in the GCC (Hassanien et al., 2012). Another study conducted by Omar Abboud (2006) to describe the status of chronic kidney failure in the Middle East concluded that few countries of the Middle East published data on incidence, prevalence and outcome of treated patients with advanced kidney disease. Oman was one of these countries that were not yet publishing in this field (see Appendix B-5, p.251 - Abboud,2006). Abboud (2006) and Hassanien (2012) emphasised the need to perform well-planned and accurate epidemiologic studies to attain accurate and reliable information on chronic kidney failure status in the Arab World and the GCC region.

In general, most of the studies published for Oman's RRT were difficult to appraise because they lack some key information on the method conducted, on the missing data, and on the limitations encountered by these studies. However, this again question the reliability of the research methods used in these studies and emphasises the hypothesis of a knowledge shortage regarding the RRT population of Oman. The Arab World and the

GCC are still suffering from some methodological deficiencies in research that need to be improved (Abboud, 2006). Also in support to this notion, the International Society of Nephrology has encouraged research on this aspect in the developing countries (Evans and Taal, 2011).

2.2 A literature review of the international picture of the epidemiology of people with RRT

2.2.1 Overview

The epidemic of kidney failure is reported by many countries of the world. The information about the incidence and prevalence of kidney failure in the western world is flourishing, due to their dynamic renal registries. Many countries, such as the UK, the USA, Australia, New Zealand, Canada, and Latin American countries, publish their renal data on chronic kidney disease/kidney failure annually. However, with regard to the comprehensiveness and the high volume of data, there are two leading renal registries in the world, which are The European Renal Association – European Dialysis and Transplant Association (ERA-EDTA) and the United States Renal Data System (USRDS). The ERA-EDTA is an international renal registry, which acts as a source for European RRT data that is produced by the national and regional renal registries in Europe (Zoccali et al., 2009). The ERA-EDTA registry analyses collected data for the 34 participating countries and publishes the results annually in different forms, such as annual reports and published summaries (Noordzij et al., 2014). Likewise, the USRDS is a registry that in 2015 included renal data for 57 countries from different continents.

Hence the epidemiology of kidney failure is published in the renal registries and many articles publishing on epidemiology of RRT population gain their data from registries, similarly this section relied on renal registries data. The following section represents the main epidemiological data published on the RRT population of the main renal registries and datasets of the world that found relevant to this study such as incidence, prevalence, death figures, and reporting the cost of RRT when available. The following information helps to present a clearer picture of RRT epidemiology and major characteristics of treated kidney failure across the world. The information included were the most recent ones that were available at the time of writing this section. The search strategy used to find these data is the direct access to the renal registries webpages. All the below listed renal registries have their annual reports published and accessible on their registries webpages.

Overall these major-below mentioned renal registries reported similar findings such as increasing in incidence and prevalence of treated kidney failure, variable rates of kidney failure prevalence across the one country regions, reduction in mortality rates and improve in survival rates, better survival rates among kidney transplanted patients compared to dialysis patients, cardiovascular disease as a major cause of death, diabetes and glomerulonephritis as major primary diseases to kidney failure and finally inconsistency in reporting some of the data such as reporting the cost of kidney failure treatment by USRDS but not by other registries. Further comparison between the data provided by these registries and the data coming from Oman are presented in Table 2-2. Also appraisal of the world renal registries is undertaken under section 2.2.7 (p. 53).

2.2.2 United States Renal Data System (USRDS)

In the USA there were 117,162 new RRT cases registered in 2013, which is equal to 363 cases of kidney failure per million population (pmp) per year. The incidence of kidney failure in the USA increased slightly compared to the previous year, which was 114,813 (353 pmp/2012) new patients. The incidence of kidney failure was variable across the states of the USA: the highest was in Southern California, at 438 pmp/2013, and the lowest were in the states of Connecticut, Massachusetts, Maine, New Hampshire, Rhode Island and Vermont, at 244 pmp/2013 (United States Renal Data System – USRDS, 2015).

The prevalence, however, was 661,648 cases of kidney failure on 31st December 2013; this is equal to 2,034 per million per year - one of the highest in the world. The prevalence in 2013 increased 3.5% from 2012. The prevalence across the USA was variable, with the lowest at 944 pmp in Alaska, Idaho, Montana, Oregon and Washington, and the highest at 1,855 pmp in Alabama, Mississippi and Tennessee. The prevalence gender ratio was 57.3% male to 42.7% female. The prevalence in different age groups was 104 pmp for ages 0-21, 959 pmp for ages 22-44, 3,624 for ages 45-64, 6,347 pmp for ages 65-74, and 6,275 for ages 75 and over, which implies that the incidence of kidney failure increases with age. The overall median age for prevalent patients could not be allocated in this report, but based on the previous data, which reported that the highest prevalence was in age groups 65 years and older, this implies that the median age would be of older age (United States Renal Data System – USRDS, 2015).

The African-American population had kidney failure prevalence 3.7 times higher than white Americans. The USRDS (2014) reported that 38% of new kidney failure patients received little or no nephrology care pre-kidney failure. Two-thirds of the American kidney failure population underwent haemodialysis therapy (63.7%), 6.8% were treated with peritoneal dialysis, and 29.2% had a functioning kidney transplant by 31st December 2013. The use of home dialysis increased in the U.S. kidney failure population from 8.9% in 2008 to 11.5% in 2013 (United States Renal Data System – USRDS, 2015).

The listed primary causes of kidney failure in the USA were the following: diabetes ($n = 52,354$), hypertension ($n = 34,104$), glomerulonephritis ($n = 9,016$), cystic kidney disease ($n = 2,557$), and others/unknown (16,386). The most common and significant comorbidity found within the kidney failure population was cardiovascular disease (CVD). In 2013, the hospitalisation rate was 1.7 hospital admissions per patient, however, in general the average hospitalisation rate for the kidney failure population in the USA is around two hospital admissions per year, secondary to cardiovascular events or infection (e.g. vascular access site infection -United States Renal Data System – USRDS, 2015).

In the USA, the mortality rate was 169 for dialysis patients, and 35 for transplant patients per 1,000 patients per year. The mortality rate continued to fall by 28% (dialysis population) and 40% (renal transplant population) since 1996 to 2013 in the USA. However, the dialysis patients continue to have higher mortality rates compared to the general population and populations with cancer, diabetes or cardiovascular disease (United States Renal Data System – USRDS, 2015).

In the U.S. kidney failure population, cardiovascular diseases are the most common cause-specific for mortality; it comprises 53% of the deaths with known causes (United States Renal Data System – USRDS, 2015). The USRDS (2015) reported improvement in survival between the years 2000 and 2008. Survival among haemodialysis patients rose from 35% to 40%, and rose from 37% to 50% among peritoneal dialysis patients. Survival was consistently higher in the kidney transplant population, from 66% to 75% among deceased-donor transplant patients, and from 75% to 87% among living-donor transplant patients (United States Renal Data System – USRDS, 2015).

The arteriovenous fistula (AVF) is the common vascular access among prevalent U.S. dialysis patients, with 62.5% of patients having this type of access by December 2013 (United States Renal Data System – USRDS, 2015).

The kidney transplant waiting list in the USA had 86,965 individuals, and the number of kidney transplants accomplished was 17,600 by December 2013. The one-year post transplant probability of survival was 95% for deceased-donor and 97% for living-donor kidney transplant recipients (United States Renal Data System – USRDS, 2015).

In 2013, there were 1,462 children who had started RRT in the USA. The prevalence was 9,921 children on 31st December 2013. Haemodialysis is the common initial treatment modality used by children in the USA (56%). In the population of children with kidney failure, identifiable leading causes were cystic kidney diseases, hereditary factors, congenital disorder (33%), glomerular disease (24.6%), and secondary causes of glomerulonephritis (12.9%). The average hospitalisation per child is two hospital admissions per patient per year. During 2009-2013, 37% of children with kidney failure had successful kidney transplantations (United States Renal Data System – USRDS, 2015).

The cost of RRT is high across the world, and the USA is no exception. The USA's Medicare increased the fee-for-service spending for kidney failure beneficiaries in the USA by 1.6%, which means the cost increased from 30.9 billion U.S. dollars in 2013 compared to 30.4 billion U.S. dollars in 2012, and accounted for 7.1% of the overall Medicare expenditure (United States Renal Data System – USRDS, 2015).

2.2.3 United Kingdom Renal Registry (UKRR)

In the UK, kidney failure incidence in 2014 was 7,411 adult patients, which means the incidence rate increased from 109 pmp in 2013 to 115 pmp in 2014. The incidence was variable across the constituent countries of the United Kingdom. The highest incidence was in Wales, equating to 119 pmp/2014, and the lowest was in Northern Ireland, at 93 pmp/2014 (United Kingdom Renal Registry- UKRR, 2015).

The prevalence of RRT patients in the UK was 58,968 on 31st December 2014, a 4% increase from 2013, so the prevalence was 913 pmp in 2014 compared to 888 pmp in 2013.

Prevalence increased across the countries of the UK, but at variable rates. The highest was in Wales, at 919 pmp/2014, and the lowest in Scotland and Northern Ireland at 874 pmp/2014 in each country. The prevalence of kidney failure was higher among males than females; however the exact figures could not be ascertained. On 31st December 2014, the median age for RRT patients was 58.7 years old. The age group distribution was as follows: 13.5 % for the 18-39 age group, 50 % for ages 40-64, 20.5% for ages 65-74 and 16% for ages 75 and above. This indicates that half of this population were in middle age, where they should have been active and productive if they had been in good health (United Kingdom Renal Registry- UKRR, 2015).

The ethnic group representing the highest percentage among prevalent UK patients was White Caucasian (78.5%), followed by Asians (11.4%), Blacks (7.6%), Chinese (0.7%), and 1.7% other ethnic groups. The registry identified that 17.8% of patients presented late at more than 90 days after diagnosis. The most common modality among prevalent UK patients was kidney transplantation (53%), followed by haemodialysis (41%), and the least used was peritoneal dialysis (6%). Home dialysis is increasing year by year, with 1,113 patients in 2013 compared to 1,080 patients in 2012 - a 3% increase (United Kingdom Renal Registry- UKRR, 2014). AV access statistics were not provided (United Kingdom Renal Registry- UKRR, 2015).

Glomerulonephritis was the most common identifiable primary kidney disease, with 18.9% of patients, followed by diabetes (16.1%), aetiology uncertain (15.8%), other primary causes (16.4%), pyelonephritis (10.6%), polycystic kidney disease (9.8%), hypertension (6.1%), and kidney vascular disease (3%), with 3.4% of patients identified as 'missed data'. The hospitalisation rate was not allocated in this report. The most common co-morbidities for this population were ischemic heart disease, peripheral vascular disease, malignancy, cerebrovascular disease and diabetes (United Kingdom Renal Registry- UKRR, 2015).

The mortality rate had declined in the UK kidney failure population from 395/1000 in 2012 to 261/1000 in 2013 (United Kingdom Renal Registry- UKRR, 2014). The survival rates among new patients on RRT in the UK improved over the last 14 years until 2013, and patients were able to live up to 10 years post-RRT. The most common causes of death among the RRT patients were cardiovascular (23%), infection related to dialysis treatment (20%) and treatment withdrawal (16% - United Kingdom Renal Registry- UKRR, 2015).

The overall number of kidney transplants in the UK in 2013 was 3,257, a 12% increase from the previous year. The mortality rate among transplanted patients was 2.4/100 patients per year (United Kingdom Renal Registry- UKRR, 2014). In the UK, there were more than 6,000 patients waiting for transplants from 2011 to 2012 (NHS Blood and Transplant, 2012-13). Variations between centres were reported regarding patients receiving transplants. Patients at a non-transplanting kidney centre tend to be less likely to receive a transplant compared to patients doing dialysis in a transplanting kidney centre in the UK, which might indicate inequitable opportunities provided for this population (United Kingdom Renal Registry- UKRR, 2014).

The prevalence of established kidney failure among children in the UK was 917 children in 2014. Prevalence was 60.4 pmp and incidence was 9.4 pmp among children younger than 16 years old. On 31st of December 2014, 79.3% of UK children with previous kidney failure had a functional transplanted kidney, 11.2% were on haemodialysis and 9.5% were on peritoneal dialysis. The most common primary kidney diagnosis in this population was kidney dysplasia ± reflux (32.6%). The survival rate for children under two years old compared to children aged 12 to 16 years old was at a ratio of 4 -1. Children with kidney transplants had higher survival rates compared to children on dialysis, at a ratio of 3-6. The overall cost of RRT was not mentioned (United Kingdom Renal Registry- UKRR, 2015).

2.2.4 Australia and New Zealand Dialysis and Transplant Registry (ANZDATA)

The incidence of kidney failure in New Zealand was higher than in Australia. In Australia, the incidence was 2,610 new kidney failure patients in 2014, at a rate of 111 pmp. New patients in New Zealand were 547 in total, and the incidence rate was 122 pmp on 31st December 2014 (Australia and New Zealand Dialysis and Transplant Registry- ANZDATA, 2015).

Prevalence was 22,234 (947 pmp) kidney failure patients in Australia, with 12,091 (515 pmp) patients on dialysis (home dialysis 9.4%, peritoneal dialysis 20.4%, in-centre haemodialysis 70.1%), and 10,143 (432 pmp) had functioning transplants. Prevalence has increased in Australia from 488 pmp in 1995 to 947 pmp in 2014. On 31st December 2014, there were 4,306 (959 pmp) with kidney failure in New Zealand, 2,678 (596 pmp) on

dialysis (home dialysis 18.3%, peritoneal dialysis 30.6%, in-centre haemodialysis 51.1%) and 1,628 (362 pmp) had functional kidney transplants. Similarly the prevalence in New Zealand had increased from 445 pmp in 1995 to 959 pmp in 2014 (Australia and New Zealand Dialysis and Transplant Registry- ANZDATA, 2015).

In Australia, there were 1,666 male patients to 944 female patients, and in New Zealand, 329 males to 218 females. Many patients in Australia and New Zealand fall within the 55 to 74 age group, similarly to the UK. The median age was 60 among Australian males and 64 among females; in New Zealand it was 61 for males and 57.5 for females. The most reported common ethnic group with kidney failure among Australians and New Zealanders was Caucasian (Australia and New Zealand Dialysis and Transplant Registry- ANZDATA, 2015).

In Australia and New Zealand, the overall percentage of new patients who referred late to nephrology in 2014 was 17% and 14%, respectively. However, for the past ten years, the overall trend of late referral decreased in both countries (Australia and New Zealand Dialysis and Transplant Registry- ANZDATA, 2015).

New patients in Australia who had diabetes at the start of RRT numbered 1,306 (50%), and in New Zealand, 216 (39%). The apparent leading cause of kidney failure in both countries continues to be diabetes, followed by glomerulonephritis (Australia and New Zealand Dialysis and Transplant Registry- ANZDATA, 2015).

The ANZDATA (2014) reported the declining use of AVG, but the stability of AV fistula use. In New Zealand, 77% of dialysis patients used AVF or AVG and 23% used central venous catheter (CVC). In Australia, the equivalent figures were not clearly identified (Australia and New Zealand Dialysis and Transplant Registry- ANZDATA, 2015).

The four top co-morbidities reported by both countries were coronary diseases, peripheral vascular diseases, lung diseases and cerebrovascular disease. The survival rate reported by both countries shows a higher rate at one year compared to five years post kidney transplantation. The mortality rate in Australia was 13.1 for dialysis patients compared to 1.9 for transplant patients, per 100 patients per year during RRT in 2014; in New Zealand it was 14 with dialysis compared to 2.6 with transplant, per 100 patients per year. The primary causes of death in Australia were withdrawal from treatment (uraemia) at 31.5%,

cardiovascular at 29.5%, other mixed causes of death (such as suicide) at 24.3%, infection at 8.9% and cancer at 5.8%. In New Zealand, the primary causes were cardiovascular at 36.7%, other causes at 21.5%, withdrawal at 19.6%, infection at 14.9% and cancer at 7.8% (Australia and New Zealand Dialysis and Transplant Registry- ANZDATA, 2015).

The kidney transplant waiting list had 1,266 patients on it by the end of 2009, compared to 1,123 on 31st December 2014. Australia and New Zealand reported the highest kidney transplant rates ever in 2014. In Australia 914 transplants were accomplished in 2014 compared to 442 in 1995. In New Zealand, 138 transplants were accomplished in 2014 compared to 94 in 1995 (Australia and New Zealand Dialysis and Transplant Registry- ANZDATA, 2015).

The incidence of kidney failure among children of Australia and New Zealand varied across the different age groups. In age group 0-4 years, the incidence was approximately the same in both countries, 10 pmp. In age group 5-9 years, the incidence was approximately 2-3 pmp in both countries. In age group 10-14 years, the incidence was approximately 14 pmp in Australia and 21 pmp in New Zealand. The prevalence of kidney failure among children in Australia is distributed between two main groups: ages 0 to 4 (24 pmp) and 5 to 14 (58 pmp). In New Zealand, the prevalence in the same age groups was, respectively, 13 pmp and 58 pmp. The primary renal disease varied across age groups but overall was glomerulonephritis and in young children was commonly renal hypoplasia or renal dysplasia. The common modality was haemodialysis in age group 10-17 years and peritoneal dialysis was more common in age group less than 10 years, and there are 20% received pre-emptive kidney transplant. The overall cost was not mentioned in the annual report (Australia and New Zealand Dialysis and Transplant Registry- ANZDATA, 2015).

2.2.5 Japan Kidney Disease Registry (J-KDR)

The kidney registries in Japan are less than a decade old. In 2007 the Japan Kidney Biopsy Registry (J-RBR) was started, followed by the Japan Kidney Disease Registry (J-KDR) in 2009 (Sugiyama, 2013). The figures for kidney failure in Japan over the years are not completed, and the recent published data found for Japan was in the USRDS 2015 report, with statistics included for the year 2013. In Japan, by the end of 2013, there were 2,411 pmp kidney failure patients on RRT nationwide - one of the highest prevalences in the

world (United States Renal Data System – USRDS, 2015). The incidence was 286 pmp per Japanese population in 2013 (United States Renal Data System – USRDS, 2015). The average age of the Japanese kidney failure population was 65.3 in 2008 (Akizawa, 2010). Japanese diabetic patients constituted 34% of the kidney failure population. The reported survival rates showed improvement, with 82% survival after one year of dialysis and 59% after five years (Akizawa, 2010). The preferred form of vascular access was AV fistula, as 95% of haemodialysis patients had this form. Deaths due to cardiovascular disease exceeded 40%, and the most common causes of death reported for the kidney failure population on dialysis in Japan were heart failure, infections, and malignant neoplasms. The life expectancy for this population compared to the general population was reduced by 50% (Akizawa, 2010). The annual crude mortality rate was constant around 9.5% among dialysis patients in Japan. There were 1,201 accomplished kidney transplants in 2008 (Akizawa, 2010).

2.2.6 Renal data from developing countries and the international scene

In South Africa, the efforts were successful in re-launching the annual renal reports after an 18 years pause, so since 2012 the South African Renal Registry has continued to publish the annual renal data about their RRT population (South African Renal Society, 2014). The last renal reports were published in 2017 including the data for the year 2015. The data showed that the South African population has increased from 40.4 million in 1994 to 52.3 million in 2012 to 54.96 million in 2015. The prevalence of RRT population increased from 70 pmp in 1994 to 164 pmp in 2012 to 189 pmp in 2015. The haemodialysis treatment is the common treatment in 2015 but not in 1994. In 1994, there were 29.8% of RRT population on haemodialysis compared to 67.1% in 2012 compared to 72.7% in 2015. Peritoneal dialysis treatment was relatively stable as 14.7% of RRT patients were using this modality in 1994 compared to 14.1% in 2012, and 13.9% in 2015. Kidney transplantation dropped significantly from 55.5% in 1994 to 18.8 in 2012 and to 13.4% in 2015. The mean age of RRT population increased from 49.3 ± 15.1 years to 51.3 ± 15 years. Male patients under treatment were more (i.e. 59.6% males in 2012 vs. 59.3% in 2015) compared to female patients. The reported causes of kidney failure in patients were the same since 2012 until 2015 and they are subsequently, Unstated or uncertain causes (34.1%), hypertensive renal disease (33.7%), diabetic nephropathy (14.4%) in 2015 (South African Renal Society, 2014; South African Renal Society, 2017).

In China, there are no complete data about kidney failure available. However, it is known that there are 120 million Chinese diagnosed with kidney disease, and one million of them are predicted to undergo dialysis by 2020 (Thomas et al., 2015). The data from the Chinese Renal Data System showed the most common causes of kidney failure on dialysis as follows, glomerular disease (57.4%), diabetic nephropathy (16.4%), and hypertension (10.5% - Liu, 2015). The kidney transplantation program showed more than 60,000 kidney transplantations since 1977 with average of 5000-6000 transplants per year (The database center of the Chinese scientific registry of kidney transplantation, 2012; Liu, 2015).

India launched its first registry for chronic kidney diseases (which includes kidney failure) in 2005 (Rajapurkar et al., 2012), and also established the first Indian transplant registry (Shroff, 2007). However, there were no up-to-date data published, and there is limited data on prevalence of CKD from the Indian context, especially there has been no longitudinal studies conducted (Rajapurkar et al., 2012). In India, there was no specific profile for kidney failure, but the country reported 52,273 chronic kidney disease patients by the end of September 2010 (Rajapurkar et al., 2012), which comprised all chronic kidney diseases together with no clear details on what proportion represented kidney failure. Also, it is known that diabetes and hypertension compromise of 40-60% of Indian CKD cases (Rajapurkar et al., 2012).

The international kidney failure scene is partially covered by two international registries, the ERA-EDTA and the USRDS. However, the USRDS has successfully included more countries in its report compared to the ERA-EDTA, which focuses on the continent of Europe rather than the other parts of the world. Accordingly, data from USRDS was favoured and presented in this section due to its comprehensiveness. In 2014 the USRDS included data from 54 countries across the world and for the first time included some data from the Gulf Countries, except for the United Arab Emirates (UAE). In 2015, the number of participating countries in the USRDS had reached a total of 57 countries compared to the 35 participating European countries in the ERA-EDTA (United States Renal Data System – USRDS, 2015).

According to the available data from the USRDS (2015), the highest incidence of kidney failure was in Taiwan (458 pmp/2013), and the lowest in Bangladesh (45 pmp/2013) (Figure 2-3). The highest prevalence was in Taiwan (3,138pmp/2013) and the lowest in

Indonesia (66pmp/2013 - Figure 2-4). Diabetes as a primary cause was the most reported in Malaysia, with 64% of patients reporting kidney failure secondary to diabetes, and least reported in Romania, at 15% of patients (Figure 2-5 - United States Renal Data System – USRDS, 2015). The most common modality used in many reported countries was dialysis, and the most common type of dialysis was in-centre haemodialysis (80% of chronic dialysis patients). In contrast, some other countries were successful in increasing the use of PD among treated kidney failure patients, such as in Hong Kong (72% of treated patients with advanced kidney disease are on PD), the Jalisco region of Mexico (45%), Iceland (34%), New Zealand (32%), Colombia (30%), and Thailand (25%). Kidney transplantation rates varied from country to country for many reasons, such as the variation in incidence and prevalence, infrastructure and organ availability (United States Renal Data System – USRDS, 2015). The highest kidney transplantation rates were reported in Croatia, the Jalisco region of Mexico, the Netherlands, Spain, Norway and the USA (53-59 kidney transplants pmp). The lowest rates were in Bangladesh, Bosnia and Herzegovina, the Philippines, Malaysia, Romania, Russia, South Africa and Thailand (1-9 kidney transplants pmp - Figure 2-6).

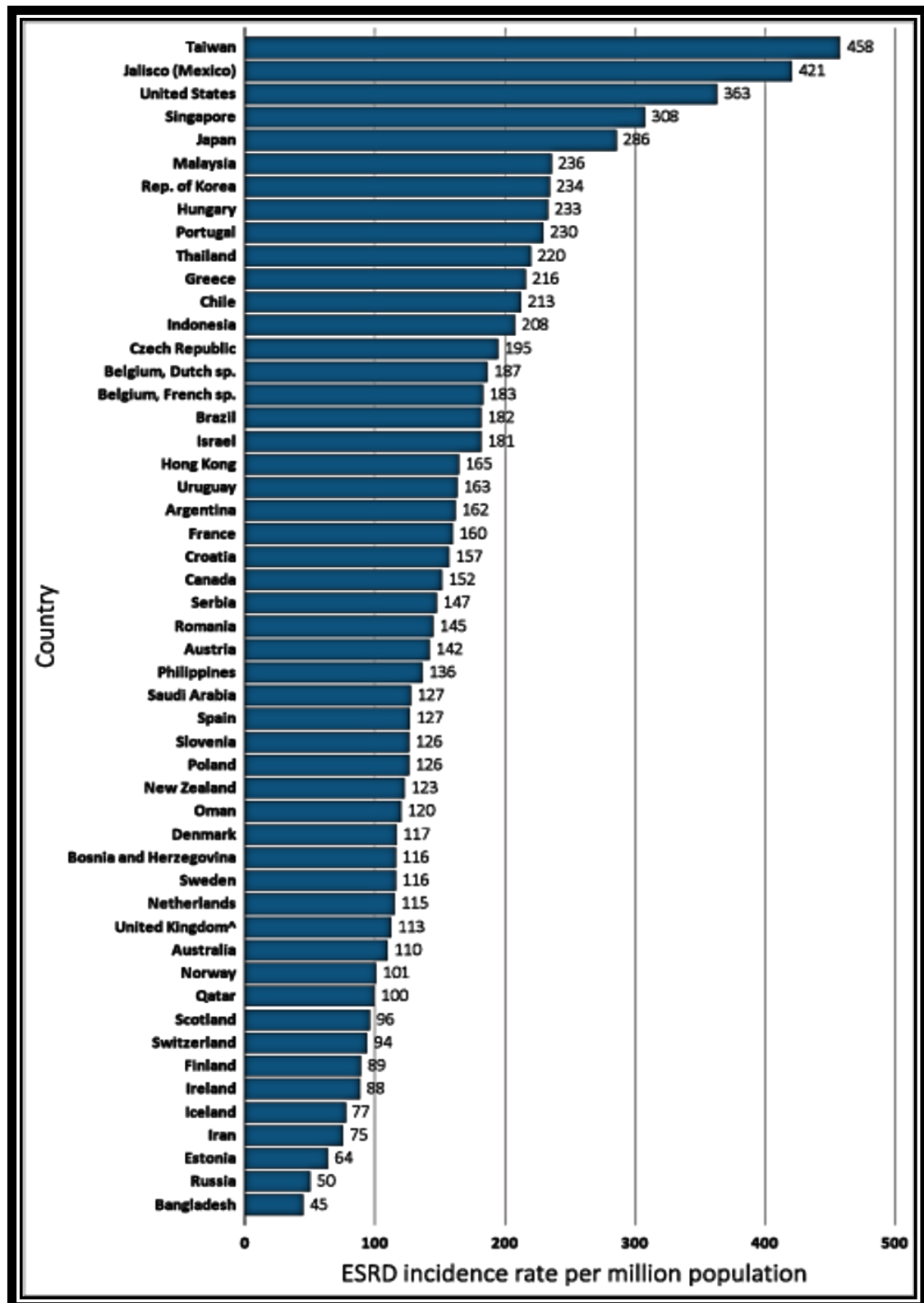


Figure 2-3 Incidence of treated kidney failure per million population, by country, 2013

©United States Renal Data System, 2015

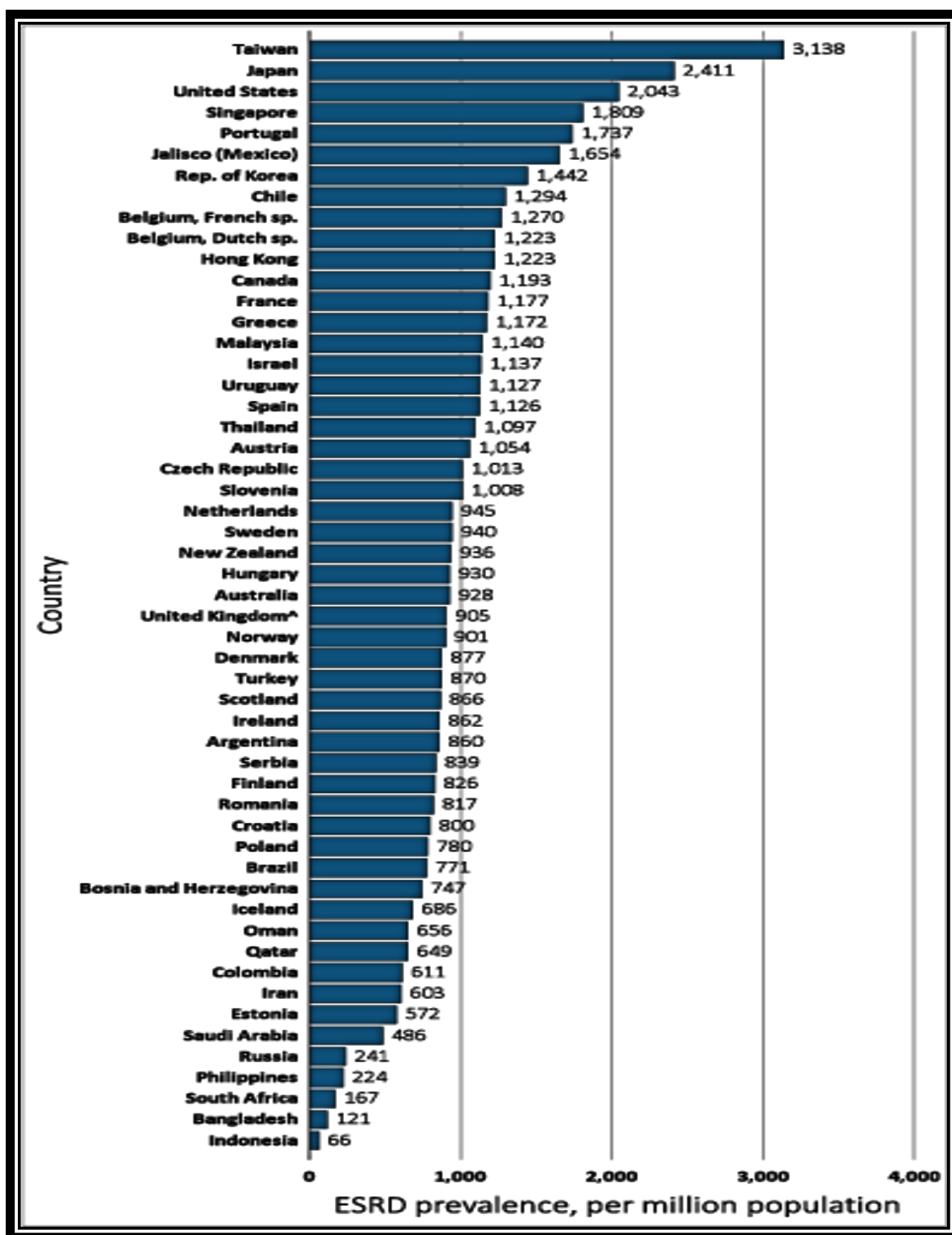


Figure 2-4 Prevalence of treated kidney failure per million population, by country, 2013

© United States Renal Data System, 2015

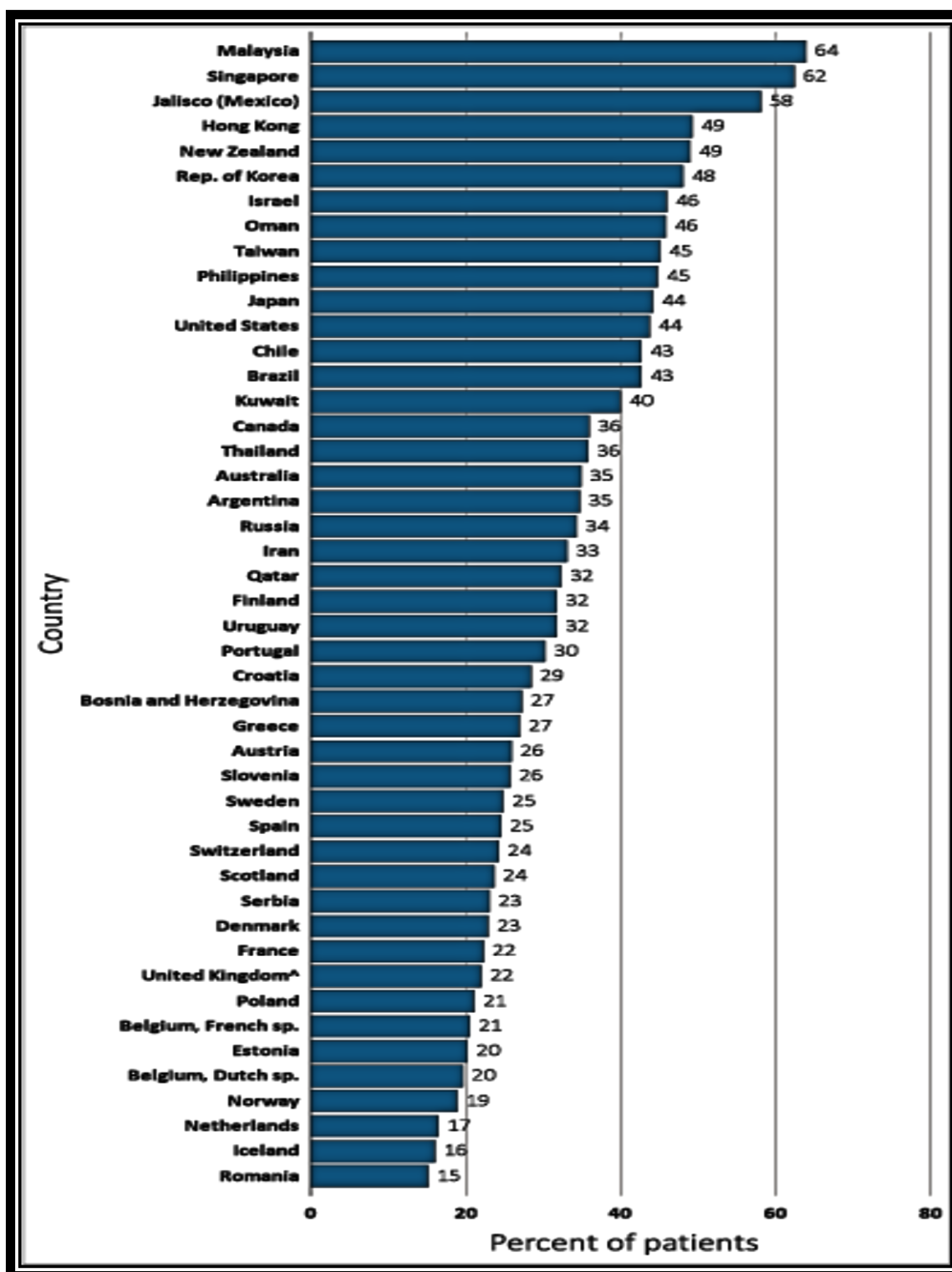


Figure 2-5 Percentage of incident kidney failure patients with diabetes as the primary kidney failure cause, by country, 2013

© United States Renal System, 2015

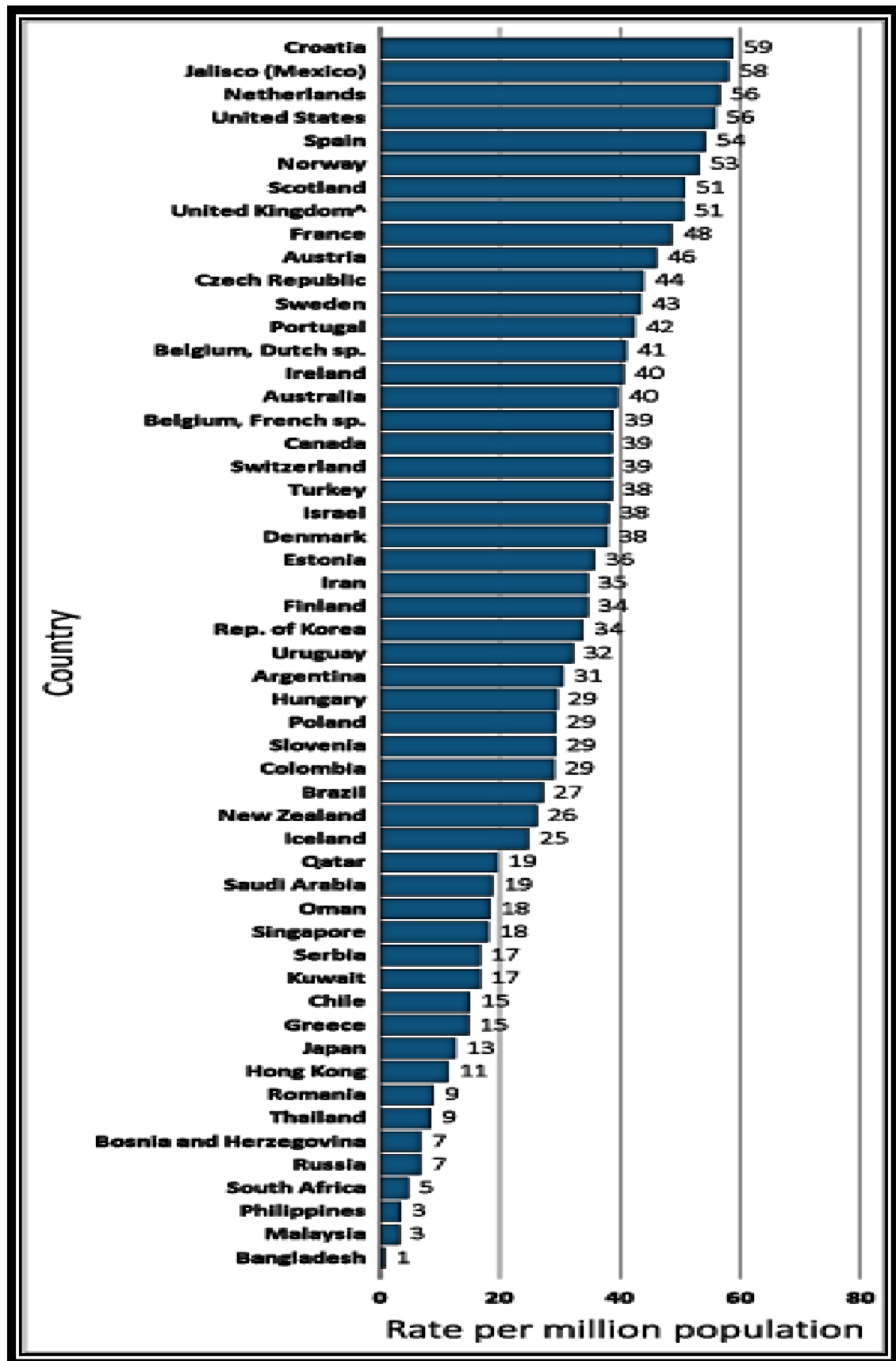


Figure 2-6 Kidney transplantation rate per million population, by country, 2013
 © United States Renal Data System, 2015

It is difficult to compare kidney failure statistics across the world for a number of reasons including the following: there are no kidney registries in some countries, and in the countries which have kidney registries there are no unified international standards for data collection and analysis across the board. In some countries kidney failure clinical and statistical analysis is absent or obscure due to other health priorities on the agenda. Poverty and/or lack of resources are further factors. There is also evidence, which needs to be tested further, showing that there is under-estimation and under-diagnoses for CKD and kidney failure in many parts of the world (Perico and Remuzzi, 2012). Finally, the results reported by the USRDS do not cover the entire world; the two largest national populations (China and India) are missing, so it can be argued that if these two populations were included it could affect the present trends and interpretation of the present data.

The Arab World (see Glossary, p.18), which have estimated population of around 390 million by end of 2015, have a limited epidemiological profile for kidney failure despite it is known that modern nephrology has been established in the Arab region since the 1960s (El-Matri, 2013). However, as far as it is known, no single kidney registry has yet been established among the Arab countries, which means there is no consistent and up-to-date data on kidney failure or CKD coming from the Arab countries (Farang et al., 2012). The kidney failure data for most Arab countries has been provided from small-scale studies which involve 100 or fewer patients and additionally include old data (Farang et al., 2012). The USRDS has covered a few Arab countries such as Egypt and the GCC, but this does not yet give the full picture of kidney failure in the Arab World.

Nevertheless, two reviews, published in the years 2006 (Abboud) and 2012 (Farang et al.), highlighted some statistics and information about kidney failure in the Arab countries and the Middle East (ME – see Glossary, p.18) Region. According to the first review (Abboud, 2006), the incidence of kidney failure ranged from 64 pmp in Yemen to 212 pmp in Qatar per annum. The average incidence was 93 pmp across the Arab countries, which meant an estimated overall incidence of 6,750 patients in the Arab countries. The highest prevalence was in Saudi Arabia, at 462 pmp, and the lowest was in Kuwait, at 80 pmp, with an average of 352 pmp (Abboud, 2006). Haemodialysis is the most common modality available, free for citizens and for \$100 (£70.49) for non-citizens. Diabetes is the leading cause reported (Abboud, 2006). There are well-established kidney transplantation programmes in some of the Arab countries, such as Saudi Arabia, Kuwait, Jordan and

Lebanon. The average cost of kidney transplantation in the first year of a person's treatment was \$15,000 (£10,574) (Abboud, 2006).

The second review, published in 2012 (some of the data included in this review can be dated back to 1992), identified the highest incidence of kidney failure in Libya, at 200 pmp, and the lowest incidence in Algeria, at 34 pmp per year (Frag et al., 2012). The highest prevalence was in Qatar, at 480 pmp, and the lowest in Libya, at 30 pmp per year (a recent study on kidney failure epidemiology, conducted in 2010 in Libya (Alashek et al., 2012) reported a prevalence of 624 pmp per annum, which was much higher than what the previously mentioned review (i.e. Frag et al., 2012) reported. The review identified three major reported causes for kidney failure, which were diabetes, hypertension and glomerulonephritis. The review expected that kidney failure incidence and prevalence in the Arab World would dramatically increase due the increasing prevalence of diabetes (major diabetes risk factors in Arab World were found obesity and lack of exercise), which was found in around eight million people in the Arab World in the year 2000 and is expected to rise to about 22 million person by 2030 (Frag et al., 2012; Abuyassin and Laher, 2016). Both reviews reported different statistics, which could be because the authors targeted different time period and may be included less or more countries. However, both reviews depended mostly on the available literature and verbal communications to uncover the ambiguous epidemiological profile of Arab and ME countries. Much of the data gathered was based on estimation, and no rigorous research methodology or designs were applied to gather the data. Also some of the gathered data goes back to the 1990s. The population in both reviews was not clearly identified, and there was a reporting bias where the author did not mention their studies' limitations. However, Frag et al. (2012) justified the shortage of their data by the fact that the data available was very limited and no Arab country had up-to-date information on the epidemiology of CKD. Both authors claimed that the data used in their reviews underestimated treated kidney failure statistics in the Arab World. This claim was supported by a systematic review published in 2012, which reviewed the epidemiology of kidney failure in the Gulf Cooperation Council and showed that the incidence of kidney failure had risen, while prevalence and mortality rates had not been reported sufficiently (Hassanien et al., 2012).

Hassanein et al. (2012) were able to include 44 studies on the epidemiology of kidney failure in the GCC. However, 40 studies were from Saudi Arabia only, one study from the UAE, one study from Kuwait, one study from Bahrain and only one study included the

GCC countries all together. The common designs of these studies were cross-sectional and cohort. None of these studies had comprehensive data that reported accurate figures of the kidney failure epidemiology of GCC countries. Hassanein et al. (2012) stated that there were no studies from either Oman or Qatar. The authors of this review recommended conducting more studies to describe the epidemiology of kidney failure in the GCC and ME because of the severe shortage and out of date data about chronic kidney disease and kidney failure in the ME and all Arabs World (Abboud, 2006; Hassanien et al., 2012; Farag et al., 2012).

Oman being one of the Arab countries, its published profile regarding kidney failure is limited. There is one study found published on the epidemiology of Oman's treated kidney failure patients (Al-Marhuby, 1998 – see Table 2-2). Also, the Oman's Ministry of Health (MOH) reported a prevalence of 1,221 treated chronic kidney failure patients who were undergoing maintenance dialysis by the end of the year 2012, but there was no incidence or other data reported about kidney failure until the end of 2013 until this study was proposed (Ministry of Health - MOH, Oman, 2014). In 2014, Oman had contributed to the USRDS report with some data mainly about incidence, prevalence, known primary causes, and kidney transplantation rates, yet these data were précised and limited and did not give the full picture of kidney failure in Oman. It would be useful if the USRDS reported the percentage of missing data coming from Oman, or any reporting deficiencies which would help to appraise the quality of the data provided.

Table 2-2 Comparison between major registries' data and Oman

Variable	USA	UK	Australia	NZ	Japan	Oman*
Incidence	363 pmp	115 pmp	111 pmp	122 pmp	286 pmp	120 pmp?
Prevalence	2,034 pmp	913 pmp	947 pmp	959 pmp	2,411 pmp	348 DP/Oman
M: F	M>F	M>F	M>F	M>F	M>F	NA
Ethnicity with ↑ KF	African American	White Caucasian	Caucasian	Caucasian	NA	NA
Primary cause	1.DM 2.HTN 3.GN	1.GN 2.DM 3.Uncertain	1.DM 2.GN	1.DM 2. GN	1.DM	1. GN? 2. DM?
Common co-morb.	CVD	CVD	CVD	CVD	NA	NA
MR	169/1000 (D) 35/1000 (KT)	261/1000	131/1000 (D) 19/1000 (KT)	140/1000 (D) 26/1000 (KT)	9.5% (D)	10%?
Mortality Cause	CVD	NA	1.Withdrawal 2.CVD 3.Others	1.CVD 2.Others 3.Withdrawal	CVD	1.CVD 2.Infection
Cost	30.9 Billion (USD)	NA	NA	NA	NA	NA

Pmp, per million population; DP, dialysis patients; ?, estimated (uncertain); ↑, high; co-morb.,co-morbidity; MR, mortality rate; NA, not available; M, male; F, female; KF, kidney failure; DM, diabetes; HTN, hypertension; GN, glomerulonephritis; CVD, cardiovascular disease; D, dialysis; KT, kidney transplant; USD – United States Dollars

*These data were obtained from Al-Marhuby's article published in 1998, and there were no updated publications on these statistics until end of 2013 when the author started this research.

2.2.7 Appraising the quality of the registries

The quality of renal registries is judged based on certain parameters, which are a good documentation system, good data collection strategy, good data cleaning, complete and non-duplicated data, accurate and valid data, clear timelines, and finally accurate data interpretation and reporting (Davids et al, 2016). Renal registries are considered a source of high-quality data because they are developed to serve a clear purpose: “to carefully monitor the quantity and quality of kidney care, and thus improve the quality and efficiency of this care” (United Kingdom Renal Registry - UKRR, 1998, p.1). Most of the registries, whenever good, sustainable funding is available, strive for good data quality and reliable technologies. They set for themselves good standards, such as a clear purpose, clear parameters, clear definitions and clear inclusion and exclusion criteria to sustain a good quality operation.

A systematic review published in 2015 (Liu et al., 2015) aimed to gain a global overview of renal registries, as the authors identified unclear and inequitable, distribution, availability and quality of renal registries across the world. The review included registries that had information on dialysis use, had more than 300 patients, and had evidence of activity between June 2007 and June 2012. The registries were evaluated according to four main standards, which were the public availability of information on dialysis, outcomes, patient characteristics, and accessibility of the registry for patients and researchers. The review (Liu et al., 2015) identified 144 registries across the globe, but only 48 of them met the inclusion criteria, 23 of which were in Europe. Seven out of the 48 gained a perfect score when measured against the standards and these seven registries were the Scottish Renal Registry (SRR), the UK Renal Registry (UKRR), the Sociedad Argentina de Nefrologia (SAN) registry, the Danish Registry of Regular Dialysis and Transplantation (DNSL), the Finnish Registry for Kidney diseases, the Uruguayan Registry of Dialysis, and the French Language Peritoneal Dialysis Registry. In general, the review (Liu et al., 2015) identified a number of gaps in the registries. For example, less than half of the identified registries around the world met the review criteria; many of identified registries had either difficult-to-access data or less suitable information for the public; the data on the burden of RRT on all levels (e.g. patients, health systems) were limited; and there was a lack of uniformity in the type and quality of data provided. The review found the majority of registries were based in developed countries, and there was a severe lack of renal registries in the Asian-Pacific region, the Middle East and Africa. Also China, Russia, and India have limited or inadequate renal registries. The review (Liu et al., 2015) recommended that all registries overcome the gaps in population coverage, data collection procedures, completeness of data and promotion of access to available data, and demonstration of good quality and standardization procedures. The evidence provided by this review was partially limited as the reported data was gathered for 2012 and published in 2015, which implies the loss of registry data that emerged between 2012 and 2015, and also the loss of any updated data on the quality of the included registries. Also active registries with no online published data could have been undetected and therefore excluded (Liu et al., 2015).

2.1 A literature review of the international state of the quality of life of people with RRT

The kidney failure disease process and its treatment, especially dialysis, have a deep impact on health care systems worldwide, and a serious impact on patients' quality of life. It has an impact on patients' physical, mental and psychosocial well-being (Murphy, 2014).

Patients can experience depression, anxiety, impaired sexuality, loss of productivity and poor coping mechanisms (Perico and Remuzzi, 2012; Murphy, 2014). Also, patients can experience complications pre and post dialysis, including poor appetite, swollen ankles, feet or hands, shortness of breath, insomnia and itchy skin (National Health Service – NHS, 2015). Literature had agreed on the lower quality of life of haemodialysis patients compared to healthy people and even compared to peritoneal dialysis patients or kidney transplanted patients (Abdel-Kader et al., 2009; Clement et al., 2009; Cruz et al., 2011; Wyld et al, 2012; Rogan et al., 2017; Shafiee et al., 2017).

A systematic review, meta-analysis and meta-regression of peer-reviewed published studies and of PhD thesis was published in 2012 (Wyld et al., 2012) and found in total 190 studies published until 1st of December 2010, reporting 326 utilities and from over 56,000 patients. The review found that kidney transplantation patients reported improved quality of life (i.e. mean utility of 0.82 – 95% CI: 0.74, 0.90) and home-based automated peritoneal dialysis may improve quality of dialysis patients' life (i.e. mean utility 0.80 – 95% CI: 0.69, 0.91) more than other forms of dialysis like haemodialysis (mean utility 0.69 – 95% CI: 0.59, 0.80 - Wyld et al., 2012). This systematic review has some limitations such as the treatment was not randomly assigned, and the data available from the included studies was not standardised in the amount of the data available, which may affect the accuracy of the algorithms used in this review.

Another study (conducted between April 2010 and January 2013) compared 143 CKD stage-5 patients with a control group of 83 healthy individuals treated for essential hypertension (HTN), found significantly lower HRQoL SF-36 scores in CKD group compared to the healthy group. The physical component score was 45.0 vs. 53.9 (i.e. CKD vs. HTN), $p < 0.001$; and mental component score was 46.9 vs. 54.9, $p < 0.001$, which indicates significant difference in the statistical scores of physical and mental components meaning lower QoL scores for dialysis cohort (Rogan et al., 2017). In addition to this study, there is much evidence supporting the lower quality of life of haemodialysis patients (Abdel-Kader et al., 2009; Clement et al., 2009; Cruz et al., 2011; Wyld et al, 2012; Rogan et al., 2017; Shafiee et al., 2017). A very recent systematic review and meta-analysis study (included 60 studies with a total of 15,575 participants) aimed to uncover the psychosocial and lifestyle status of young adults (i.e. 16-30 years old) receiving RRT found lower quality of life in dialysis patients', especially limited employment, independence, and relationships (Hamilton et al., 2017). The study results included in this systematic review

were highly heterogenic and appeared to be biased toward surviving participants and had limited comparing scale due to the small evidence base for the measured variables (Hamilton et al., 2017).

All treatments and health care are made to achieve an improvement of health related quality of life of patients. Yet assessment of the improved quality of life can be controversial due to its subjectivity as it is relatively based on the patients' answers.

2.1.1 Economic burden on the health systems

In the USA, there were over 400,000 treated chronic kidney failure patients on haemodialysis, with around US \$90,000 (£62,496) spent per patient per year in 2012 (Kidney Disease/Improving Global Outcomes – KDIGO, 2015; Saran et al., 2015). The cost of kidney failure care exceeds 6% of the total costs of the American health care system (Thomas et al., 2015). According to Thomas et al. (2015) the countries that will be affected financially by the increase in prevalence of kidney failure are the countries with high rates of health care spending, which could be right as health care spending is already high with the current situation then this will be magnified with increasing prevalence and cause great loss and drain on health budgets.

The calculation of direct and non-direct costs has not been studied extensively in the literature. One study conducted in Saudi Arabia calculated the cost of an average of 2500 haemodialysis sessions delivered for 200 patients from 1st January 2007 to 30th June 2010 (Al Saran and Sabry, 2012). The direct costs, defined by this study as the cost related to dialysis treatment, such as the cost of dialysis disposables and drugs, staff, out-patient medication, laboratories and direct services. The non-direct costs were those for building, maintenance and engineering, housekeeping and administrative personnel. The study found that the total cost of the dialysis session was USD 46,332 (£32,173) per patient per year. The direct costs represent 81.5% and the non-direct costs the remaining percentage (Al Saran and Sabry, 2012). This cost calculation remains, however, below the average cost for developed countries due to different factors such as the variation in local labour cost and variable standards of care (Al Saran and Sabry, 2012).

The most cost-effective treatment for kidney failure is kidney transplantation. Thomas (2014) stated that the financial cost of the kidney transplantation in its first year is equal to a year's cost of dialysis, after which the cost of dialysis rises over transplantation because it is a prolonged treatment. However, the option of kidney transplantation is faced with the challenge of limited kidney donors, increasing the number of people on kidney transplant waiting lists and increasing commercialism.

2.2 Prevention and screening programmes

The value and importance of preventing chronic kidney disease/kidney failure are widely recognised across the world. Preventing kidney failure means preventing its causes and managing its risk factors. Currently, there is ample evidence in the literature demonstrating the role of diabetes mellitus as a major cause and risk factor for kidney failure (Perico and Remuzzi, 2012). The prevalence of diabetes is alarming, and according to the WHO, it was estimated that 171 million of the world's population had diabetes in the year 2000. At the current rate this is expected to rise to 366 million (298 million in developing countries) by 2030, which represents 6.5% of the world's population (Perico and Remuzzi, 2012). Therefore kidney failure prevalence is expected to double, and exert more of a burden on health systems around the world, unless the international community act to prevent diabetes soon. World Health Organisation has set out a global non-communicable disease action plan to prevent diabetes and other chronic diseases, which should be achieved by the year 2020. The plan aims to prevent or reduce the frequency of four modifiable risk behaviours that were found to be linked to diabetes, cardiovascular diseases, cancers and chronic respiratory diseases, namely tobacco use, unhealthy diet, physical inactivity and harmful use of alcohol (World Health Organisation - WHO, 2017).

In 2012, the Renal Association published clinical practice guidelines for detection, monitoring, and care in relation to chronic kidney disease. This document conveys important messages to primary care providers and it helps to improve the outcomes and reduce the complications expected if implemented well. Additionally, the world has tried some detection and management programmes for chronic kidney disease such as a web-based programme called KHDC which aims for the "detection and management of kidney diseases, hypertension, diabetes and cardiovascular disease in developing countries". This programme was developed by the ISN (International Society of Nephrology), which was

reported to screen around 42,000 people in 25 developing countries (Atkins and Zimmet, 2010). There were limited published information on KHDC programme to know for example more about the characteristics of the sample and what was the inclusion and exclusion criteria and also more knowledge are needed to appraise this programme. It is not clear whether this programme has been evaluated, but it is known that it has been reviewed by ISN experts and used in 25 countries. Also this programme has a global template that can be adapted and consulted at http://www.nature.com/isn/education/guidlines/isn/pdf/ed_051027_2xl.pdf (Persy et al., 2008). However, it was not possible to access this template and on the ISN webpage. So due to the shortage of information on this programme, it is difficult to appraise its quality.

Another programme is KEEP (Kidney Early Evaluation Program), which was initiated by the National Kidney Foundation in the USA, aiming to screen people at risk of kidney disease in the U.S. communities (Atkins and Zimmet, 2010). The KEEP survey has been used to screen thousands of participants since the year 2000. For example 61,675 participants with diabetes, hypertension, or a family history of kidney disease or diabetes or hypertension were screened using the KEEP survey from 1st August 2000 until 31st December 2006. The survey found that 16,689 (27.1%) participants had chronic kidney disease (Whaley-Connell et al, 2008). There was no study known to have tested the validity or reliability of the KEEP survey, however, a number of factors imply its good quality. Firstly, the survey was used in a national programme, which usually takes a very significant amount of time to prepare and to be reviewed by panels of experts. Secondly, the survey has been frequently used since the year 2000, tested and retested on participants with numbers ranging from 6,071 to 61,675 participants, and by different researchers (Brown et al, 2003; McCullough et al, 2007; Stevens et al, 2010). Thirdly, no authors identified any shortcomings in the survey, except one (McCullough et al, 2007), who commented on the use of dipstick urine for microalbuminuria detection and found that instead it was best to do urine-creatinine ratio. This recommendation was undertaken in the later KEEP programmes. All of this implies that the KEEP survey has been scrutinized thoroughly over the years, and therefore adopted by many researchers. However, it can be argued that though this programme has been successful in the USA, it could fail if used in a different context such as the Arab World. Therefore, the KEEP programme, if to be used in a different context, should be examined and tailored to the individual needs of individual nations (Atkins and Zimmet, 2010).

2.3 Conclusion

Up to this point many and different notions have been elucidated, such how the world is divided between countries that have kidney registries and others that do not. The kidney registries have been found to guide authors, health care providers, financial analysts, decision makers, and whomever else it may concern, to improve knowledge and consequently prevent kidney failure and manage patients with kidney failure around the world. Also, it helps leaders to plan for kidney replacement therapy and health care for a population with such demanding care needs.

From the international renal registries such as USRDS (2015), the renal community has such significant data. For example, the registry reported that the highest incidence and prevalence of treated chronic kidney failure among participant countries was Taiwan. Researchers need to investigate the causes and risk factors that led to this outcome in this nation, and other nations that have higher figures, such as the USA. Also, on the other hand, researchers can study the nations that have lowest incidence and prevalence of treated chronic kidney failure to learn how such good practices can be transferred to other nations aiming to reduce the occurrence of kidney failure. Certainly, having this information can guide other systems towards modifying their programmes in dealing with this disease.

The creation of a kidney registry needs funding, resources and a committed, consistent and quality data collection team. It requires people to value the data as empowering, have the view that no health system or other system in the world can be upgraded or act efficiently without investing in research and the data collection of large datasets. In the first place, it needs data to be made available. This puts a responsibility on all the countries of the world to gather data about their kidney failure population and make it accessible and available as published material for the patients and the research community.

Oman shares this responsibility with the world, and it needs to invest more in chronic kidney disease/kidney failure research and publication, especially to study the risks and causes of kidney failure and then the impact of the disease on patients and systems. Nevertheless, Oman is recognised for its good health system, which provides good primary, general and nephrology health services for the public. Also expanding of general health and renal services are missions for Oman's MOH. However, the health sector in

Oman and around the globe does have some challenges, which have to be identified so that they can then be overcome. Accordingly the following chapter provides more details about the context of Oman and its health sector challenges.

3 Oman's background and context

3.1 Introduction

This chapter describes the background of Oman. Understanding the background of Oman will enable the reader to visualize how the health sector of Oman is situated within the whole picture of the country, as nowadays health cannot be isolated from the surroundings. Health can be affected by many external factors such as political, economic, social, technological, legal and environmental factors (PESTLE framework - Marmol, 2015; the Ministry of Health – MOH, 2014). All these are external factors which the MOH may not be able to control, but which could have an impact on its operations. Therefore, identifying these external factors could help in better management and control for the delivered services and provide deeper insight on planning for the future services.

Additionally, as the setting of this study is Oman, some information is purposely mentioned in this chapter because it is connected to the data discussed later in the results and discussion sections. From these perspectives, this chapter provides the information necessary to understand the life of the Omani people and the surrounding factors which could affect Omanis' life and health. The PESTLE framework is used here to outline these factors.

The PESTLE framework appeared first in 1967, developed by Professor Francis J. Aguilar, and he called it "PEST analysis". The PEST analysis was later updated by many researchers and called PESTEL or PESTLE analysis or framework (Marmol, 2015). This framework is used widely for observing all types of organisations for the purpose of better understanding the present situation and overseeing the future to facilitate planning (Marmol, 2015). Similarly, this framework is used here to understand the reality of Oman in relation to each component of PESTLE. So the remainder of this chapter is discussed under each component of the PESTLE framework.

3.1 Political and administrative status

Oman is included as a Middle Eastern country and an Arab world state. Politically, it is considered among the most peaceful nations in the world, and it has very good

relationships with all countries. The Sultan of Oman (the king and ruler) does not believe in war but sees peace as a foundation of his governance.

Oman is located at the South-Eastern corner of the Arabian Peninsula (The National Centre of Statistics and Information – NCSI, 2015). It has an area of 309,500 square kilometers (almost the size of Poland or Italy), which is bordered by Yemen, Saudi Arabia, and the United Arab Emirates (UAE). Oman's coastline is about 3,165 kilometers starting from the Strait of Hormuz and extending to the Arabian Gulf, the Sea of Oman, and the Arabian Sea (The National Centre of Statistics and Information – NCSI, 2015). Oman shares the coastline of the Arabian Gulf with UAE, Qatar, Bahrain, Kuwait, and Saudi Arabia. Therefore, the six of them are called Gulf Cooperation Countries or GCC.

Oman is divided into eleven governorates and these governorates are divided into 61 states or districts. These governorates are named in this thesis as the capital which is composed of six districts; the south which is composed of ten districts; the peninsula which has four districts; the east subdivision 2 which has six districts; the east subdivision 1 has five districts; the west consists of three districts; the interior has eight districts; the middle has four districts; the west end has three districts; the north subdivision 1 which consists of six districts and the north subdivision 2 has six districts (the 12 districts of the north governorates were used in this research as locations).

Oman, in general, has sound leadership and management systems, which try to respond to the populations' needs. Accordingly, the health needs of the population were always a priority of the government. Therefore, one of the first established ministries in Oman was the Ministry of Health established on 22nd August 1970, and one of the health priorities addressed after establishing the health infrastructures and fighting communicable disease was chronic diseases including renal diseases. The first MOH aims were set at that time "to provide health services to all regions of Oman; to carry out a program of preventive medicine; to undertake health education, and to train personnel involved in health care delivery from doctors to technicians" (Al-Kharusi, 1995).

The Oman's MOH was the first ministry among all ministries of Oman to release an operational manual to guide the health services delivered by the ministry personnel. Major developments have taken place in the health sector since the renaissance launched in Oman in 1970, inspired by His Majesty Sultan Qaboos bin Said (The current king of Oman since

1970). There was an emphasis on building the best possible infrastructure for the health services. Consequently, there were many hospitals and health centres opened, and there was an increase in the workforce of the health sector in Oman. For example in 1970, there were 20 clinics, two health centres, and four hospitals, but no special renal care institutions. By 1980, there were 54 clinics, 11 health centres, 14 hospitals and four other smaller health institutes, and at this point the renal treatment was started in Oman. As a result, the number of outpatients increased from about 24 thousand patients' visits in 1970 to about three million patients' visits in 1979 (Al-Mughairy, 1985; Al-Kharusi, 1995).

By 1976, nearly all hospitals in Oman had a telephone, which improved the communications among different health institutions. The MOH in Oman joined the World Health Organisation (WHO) in 1971, but the WHO's office was opened in Oman only in April 1975. Moreover, the ministry established a close affiliation with the Royal College of Physicians and Surgeons of Glasgow, the Universities of Glasgow and Edinburgh, the Institute of Child Health, London, and the Oxford University, to send young Omani doctors for further training and specialisation in these institutions (Al-Mughairy, 1985).

Since the late 1970s until the present, the health services in Oman developed rapidly and made major steps in providing good health services available for Omanis. The MOH funds the entire public health sector in Oman, so it was a national public-care model (Ministry of Health – MOH, 2014). In 2013, the public sector was composed of 49 hospitals and 195 other health facilities (Ministry of Health – MOH, 2014). There were five other hospitals and 50 other health facilities, which are public but managed by other authorities such as the Royal Oman Police and Sultan Qaboos University. Also by this point, the MOH expanded the renal dialysis services to cover main regions of Oman through building 18 renal dialysis centres across the county. The private sector owned 12 hospitals, 1026 clinics, and 537 pharmacies. The private sector health services are monitored by MOH (Al-Mughairy, 1985; Al-Kharusi, 1995). The total workforce for public and private sectors was 7,673 physicians and 16,930 nurses at the end of 2013 (Ministry of Health – MOH, 2014).

The current main mission for the MOH is “to enhance the health and wellbeing of all the people of Oman by ensuring the availability of comprehensive health services throughout the Sultanate” (Ministry of Health – MOH, 2014). The ministry puts huge efforts and funding into the good planning of health services (including renal services), into education and training, and into development and research of all health concerns including renal

diseases, however, it is also a critical responsibility of the ministry to manage its expanding services, and the consequent increases in demand for human resources, technology, medical and other resources (Ministry of Health – MOH, 2014). The general population and the renal sub-population of Oman are exerting increased pressure on the health sector to respond to their needs and demands. The ministry in response had increased the number and the quality of renal care since 1980 and until present as it will be illustrated later on in this thesis under the results of study one (see p. 90).

3.2 Economic status

Oman is a high-income country (Ministry of Health – MOH, 2014). Oman's economy depends on oil, gas, trade and budget surpluses. At the end of March 2015, Oman had 1.7 billion OMR (3.1 billion GBP) net oil revenue. Oman exported 344.4 million oil barrels in 2014, mainly to the USA, Japan, and Korea compared to 283 million oil barrels in 2005, (The National Centre for Statistics and Information - NCSI, 2015).

Additionally, Oman depends on non-oil resources to support its economy, for example, mining, tourism, agriculture and fish exports. Oman produces minerals such as chromite: 142.2 million OMR (255.4 million GBP) was the total value of the mineral produced in 2014. Agricultural goods production was 1,514 tons in 2014 compared to 989 tons in 2005; the fish production was 211 tons in 2014 compared to 158 tons in 2005 (The National Centre for Statistics and Information - NCSI, 2015). Omanis who live on the coast depend widely on fish and seafood as a source of income and as a main source of nutrition. However, this may change since fast-food is now widely accepted and eaten among the younger generation of Omanis which might have a negative impact on population health in general and may help in seeing more of kidney diseases among young population.

Oman had rapid economic growth especially in the years 2006-2010 where the Gross National Income (GNI) jumped from 8.3% in 2000 to 11.1% in 2010. The GNI has decreased relatively since 2011 (Ministry of Health – MOH, 2014), and that may possibly be due to the decline in oil prices. Oman is actively trying to invest in non-oil resources to avoid any fluctuation in the income of the country.

The total expenditure for the Oman's MOH increases steadily on an annual basis. In 2003, the MOH expenditure was 148.9 million of OMR, and this was 5.4% of total government expenditure (The National Centre for Statistics and Information - NCSI, 2015). In 2013, the MOH spent 593.7 million OMR, which was more than a 400 million OMR increase in spending, but it was equal to only 5.5% of total government expenditure (Ministry of Health – MOH, 2014). Oman was one of the three lowest spenders on health services among the Gulf member states (Ministry of Health – MOH, 2014). Also, it is not known the amount of expenditure on renal care so far, because the MOH did not include this in the annual MOH health report or any other publications.

3.3 Socio-cultural status

More than 90% of Omanis are Muslim and Arabs. The first general census of the Omani population took place in 1993, and then in 2003 and the last in 2010 (The National Centre for Statistics and Information - NCSI, 2015). The population of Oman has increased from two million in 1993 to about four million by mid-2014. The population of Oman is not purely Omanis, and there are a considerable proportion of non-Omanis or expatriates such as Indians. The percentage of non-Omani has changed dramatically from 26.8% in 1993 to 43.4% in 2014. In 2014, Oman had over 1.7 million expatriates compared to nearly 2.3 million Omanis (The National Centre for Statistics and Information - NCSI, 2015). The breakdown of the general population per governorates is available in the following table (

Table 3-1). So far, there is no statistics highlighting the kidney failure number of patients in Oman in relation to Omani population in particular or in relation to non-Omani population in particular. The available statistics are for the general population.

Table 3-1 The breakdown of Oman’s population in mid-2014

Governorates	Total *Pop.	Expatriate	Omani	Area (Km2)	Pop. Density (Km2)
The capital	1,210,480	740,395	470,085	3,900	310.4
The north subdivision 2	655,873	209,429	446,444	12,500	81.3
The north subdivision 1	360,521	89,773	270,748		
The east subdivision 1	267,322	85,663	181,659	36,400	14
The east subdivision 2	242,131	84,920	157,211		
The interior	655,873	92,238	310,774	31,900	12.6
The west	185,596	48,293	137,303	44,000	4.2
The west end	99,836	50,142	49,695	-	-
The south	377,506	188,005	189,501	99,300	3.8
The middle	40,936	18,942	21,994	79,700	0.5
The peninsula	39,813	14,521	25,292	1,800	22.1
Not stated	109,867	109,867	0	-	-
Total	3,992,893	1,732,188	2,260,705	-	-
*pop., population, the governorates highlighted in blue were the settings of this research					

The most densely populated governorates are the capital followed by the north subdivision 2 and the south (Figure 3-1). The Omani population is a young population where ~90% of the population is under the age of 50. The age group 0-19 years are 44.8% (~ one million); 20-49 years are 44.3 % (~ one million); and 10.9% (~ 250 thousand) are aged over 50 years old. Omani males to females are in this ratio (males) ~1.14 million: (females) ~1.12 million and in percentage the ratio respectively 50.6%:49.4% (The National Centre for Statistics and Information - NCSI, 2015).

The last formal census conducted in 2010 showed that the size of families in Oman is large with an average of 7.8 persons per family. Oman still has an extended-family framework where sometimes the grandparents, parents, and children live together in one large house. The Omani World Health Survey conducted in 2008 showed the median monthly household income was 360 OMR (643.5 GBP) and 81.2% of Omanis get their income from wages and salaries. In a survey called “Household Expenditure and Income” survey, which was conducted in 2010-2011, results showed an increase in the median monthly income to 904 OMR (~1,616 GBP - Ministry of Health – MOH, 2014).

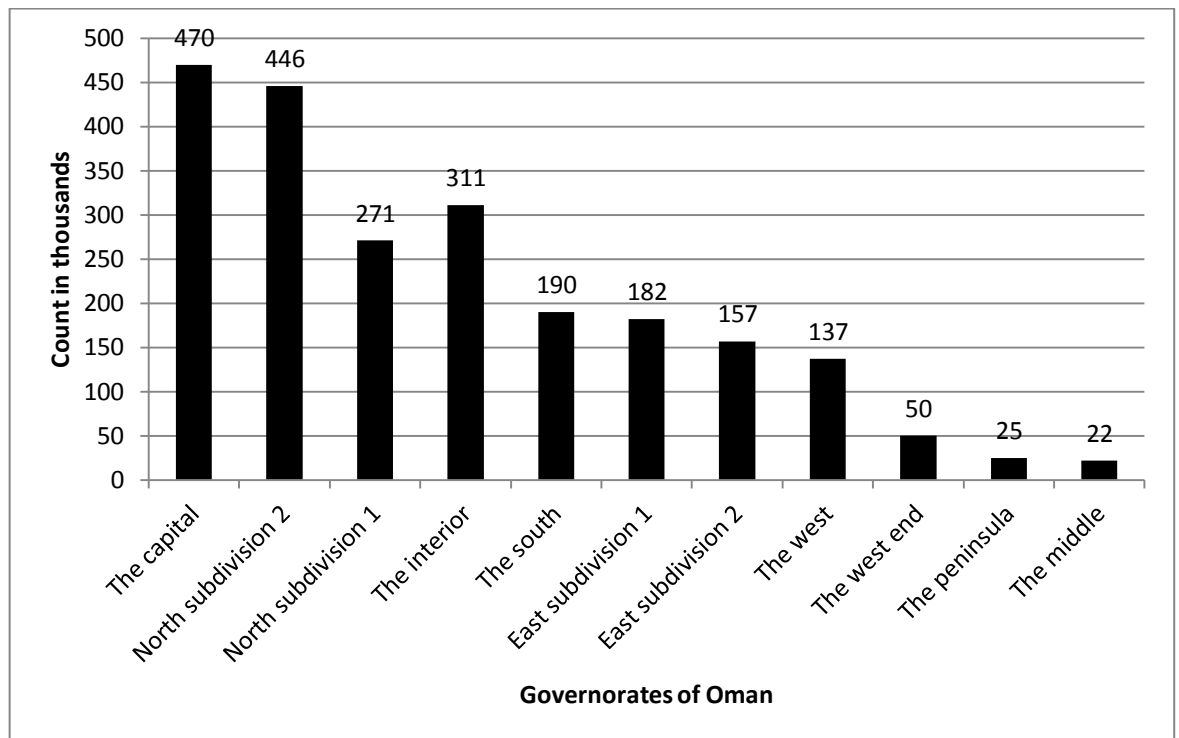


Figure 3-1 Omanis population distributed across governorates of Oman, 2014

© National Centre for Statistics and Information, 2015

In general, Oman provides good general services for its population. Most Omanis work in civil services mainly in education or health and in defense/military sectors. In 2012, Oman had ~ 1.7 million workers, 85.8 % were Omanis (Ministry of Health – MOH, 2014).

Oman has two main types of education, the basic education which is on three levels: level 1 (primary) grades 1-4 (ages 6-9 years old); level two grades 5-10 (preparatory, ages 10-15 years old); and level three 11-12 (Secondary, ages 16-17 years old). There were more than half a million Omani students (~596 thousands) enrolled in basic education in the academic year 2014-2015. Also, Oman has provided literacy centres for people who are not able to enroll in the basic education systems because of many and different reasons such as old age and job commitments (The National Centre for Statistics and Information - NCSI, 2015). There were 908 literacy centres in the years 2012-2013 serving nearly ten thousands students, of which 97% of these students were women. The illiteracy rate in Oman appears to be declining since 1970s and until 2013 as the illiteracy rate among 15 year-old Omanis reduced to about 14% by 2013 (Ministry of Health – MOH, 2014).

The other type of education is higher education, where the graduates of basic education go next to pursue their education and training to be prepared to work in the business market.

The higher education can be vocational training centres, fishing institutes, applied sciences colleges, technical colleges, military and security colleges, institutes of health and law, and university education. Currently, Oman has only one public university called Sultan Qaboos University, but there are a few private universities such as Nizwa University (Ministry of Health – MOH, 2014). Education is an important pillar for country development as a whole and for health development in particular either for the general population or for the renal sub-population. Government expenditure on education was 8.7% in 2014 compared to 9% in 2010.

3.4 Technological Status

Technologies in different forms, like data technologies, communication, electricity, and transportation, are well represented and available in Oman. Oman is well connected externally with the world by two international airports, one in the capital and the other in the south governorates (The National Centre for Statistics and Information - NCSI, 2015). There are three sea ports in Oman in the north, in the south and in the capital governorates. Oman internally is well connected by good road networks. Most people of Oman use cars for transportation. The country has a good national bus service that's mainly in the capital, and which is mostly used by expatriates, there are no trains or undergrounds (Ministry of Health – MOH, 2014), but there is a plan in place to launch train transportation across the GCC countries as soon as possible. However, most Omanis own cars and it is the main mode of transportation. It is very rare to see people walking to their destinations in Oman, which has contributed to low physical activity among the Omani population.

Telecommunication services are well provided across the country. The people in Oman have become more aware of the practicality of mobile phones and therefore the subscribers increased about thirty-two-fold between 2000 and 2012, while internet subscribers increased fourfold within the same period (Ministry of Health – MOH, 2014). The government of Oman is interested in adopting the new technologies that benefit the development of the country. Therefore, an Information Technology (IT) authority was established in 2006 called “Information Technology Authority” to supervise and implement the IT evolution in Oman. Nowadays there is an ambitious IT project taking place in Oman called e-government, where the country is trying to transform the paper-based work to become an electronic-based business (Ministry of Health – MOH, 2014).

In contrast to the present high standards of technology and infrastructure, in the past the people in Oman faced great difficulty by not having modern roads, electricity, and telecommunications services. For example, the physicians and nurses had to travel occasionally to outreach patients who lived in remote places like the north governorates. There were no modern highways, which meant that the travel mission of health personnel was undertaken with great difficulty. These medical tours could take 7-10 days of travel by a four-wheel Land Rover vehicle. Also, there were many patients (including kidney disease patients) who died while they were escorted to the capital for medical treatment on old trucks, donkeys or camels. Moreover, the lack of telecommunication devices like telephone created massive delays in delivering the health services to patients around the country at that time (Al-Kharusi, 1995). Also, with no proper form of electricity before 1970, patients and health workers could not find relief from the harsh heat of Oman's climate, especially during summer. The harsh-hot weather that is prominent in Oman could be one of the factors led to frequent body dehydration and therefore frequent kidney problems that might cause kidney failure.

Currently, all the hospitals and health facilities have very good services of electricity, telecommunication, technologies, and they are very well connected by asphalt roads. However, the internet revolution is progressing fast, and the authorities in the health sector have to continue appraising this and all available technologies, to cope with the international development and to satisfy clients' needs. Nowadays health sector facilities can be connected with a country network where patients' data can be accessed anywhere. However, this advancement is under development and not yet fully accomplished in Oman. Also, the Oman's MOH has an e-health portal where all essential information about the ministry and districts' hospitals are available. This portal is comprehensive and communicates many types of information such as the services and latest news of the Oman's MOH. It presents statistical reports and some research studies' results. Though this e-portal is useful for general information gain, but regarding the renal care is of limited use because it is not specialized e-portal and there is no renal database included and no specialised educational programmes are structured for renal concerned parties within this e-portal.

3.5 Legal status

The basic law of the country is implemented by all the citizens and people of Oman. The “Supreme Council of Justice” and the “Supreme Courts” are the bodies ultimately responsible for making sure that the law is implemented and protected by everyone living in Oman. The “Basic Law of the State” was last reviewed and updated in 2011 (Ministry of Health – MOH, 2014).

The Oman Ministry of Health has its policies and rules which are governed by the general law constitution of Oman. The right of the patients and workers in the MOH are protected by law. The Health Minister is the highest authority, in MOH, who has to ensure the running of the right laws in place, and he is assisted by three undersecretaries, and they are respectively the undersecretaries of; planning, health affairs, administrative and financial affairs (Ministry of Health Oman - MOH, 2016). The MOH has the needed laws and rules to regulate the health affairs in Oman and the renal services in particular. However, the big challenge facing the MOH is ensuring that the employees and the clients stay informed of the rules and regulations of the ministry at all levels of the organisation (Marmol, 2015).

3.6 Environmental status

Oman consists of different topographical areas such as plains, wadis or dry river beds and mountains (Ministry of Health Oman - MOH, 2016). The plain extends on 3% of Oman’s land area; the mountains area is about 15%, and the sand or desert area is about 82%. Most people of Oman live in the plains and mountain areas (National Centre for Statistics and Information - NCSI, 2015).

The climate of Oman is variable across the governorates, and it is different in summer than winter, as those are the two seasons experienced in the country. In summer the weather is hot and humid in the coastal areas, and it is dry and hot in the interior areas. The weather is pleasant in the mountains, with cold periods in winter, and in the south of the country. The temperature varies from -1 to 49° C. The humidity ranges between 2 to 100 % (The National Centre for Statistics and Information - NCSI, 2015).

The rain falls irregularly, but heavy rains can fall at some times of the year. The south governorate is an exception, which has regular and heavy rains between June and October.

The rainfall reported in millimeters in 2014 ranges between 0.4 mm to 274 mm across the country (The National Centre for Statistics and Information - NCSI, 2015). Oman depends widely on the purification of sea water or “desalination plants”. Currently, Oman has a 4500 km long piped network where the treated water is distributed among households. The data showed that 87% of population use safe drinking water and 77% use safe water in general in 2010 (Ministry of Health – MOH, 2014). Accordingly if that later percentage (77%) is accurate, then it is worthwhile to investigate the impact of unsafe water on the remaining 23% of the population especially in relevance to occurrence of kidney diseases.

Also, Oman has a unique method of water channels called “Falaj”. It is an ancient method established by old Omanis and yet still used. The old Omanis made Falaj to transport the water falling from the mountains or underground to the earth surface and so this water is carried by Falaj channel under the earth’s natural gravity to reach mainly farms. This water is pure water and is used for different purposes such as drinking and farm irrigation. Oman has Over four thousands Falajs, but only ~ three thousand are currently in use (Ministry of Health – MOH, 2014).

An important point to mention here is the effect of cyclones and earthquakes on Oman, which is usually very limited. Oman has had five known cyclones in its history and these are; 1977 Oman cyclone, 2002 Oman cyclone, 2007 Gonu, 2010 Phet, and 2011 Keila. The cyclone in 1977 caused some damage where it killed around 105 people and left ~ 50 thousands homeless. The major damage caused by a cyclone in recent years was Gonu in 2007. Gonu killed 50 people and cost some few billions of U.S. dollars in damage (Ministry of Health – MOH, 2014). These natural disasters can delay patients from seeking medical attention during these disasters and can delay kidney failure patients from attending their dialysis sessions.

The Oman’s Ministry of Regional Municipalities and Water Resource is the body responsible for environment, food and water safety in Oman. It has rules and regulations in place to organise, monitor and inspect the safety of the buildings, food, and water in the country (Ministry of Regional Municipalities and Water Resources – MRMWR, 2015). However, the Ministry needs to increase the awareness of Oman’s population about things like: the environmental standards they need to follow in building their houses, for example; how to save renewable energy; climate change and its impact on Oman’s weather and health; transport pollution and other types of pollution and their impacts; and the benefit of

recycling for the environment. The bad environmental factors can cause critical health problems for populations such as kidney failure which can occur sometimes because of long time lasting dehydration or drinking large volumes of contaminated water. Also, food safety is a growing concern in Oman secondary to food products deception that were recorded recently in Oman like the expired raw rice that were about to be sold for people in Oman.

3.7 Health sector in Oman

Modern medicine started in Oman sometime in the nineteenth century (Al-Kharusi, 1995) and Muscat Charitable Hospital was probably the first hospital that opened after 1910. In 1933, Arrahma Hospital in the capital was established by the American Mission, which was an American non-profit organisation in Oman. In those days there were severe shortages of physicians, nurses and other health professionals. The duty started at 6 a.m., and it might end at 9 p.m. or later. A physician could see 200-300 patients within one day, in addition to their other duties like requesting medications and other administrative work (Al-Kharusi, 1995).

Nurses undertook other responsibilities in addition to their caring roles, for example, sewing patients' gowns and planting trees in the hospital garden. The health workers at that time worked under a great deal of pressure (Al-Kharusi, 1995). Some strange situations could also be described, for example, some patients (Bedouins) preferred the outdoor space if admitted to the hospital, which means they were kept under the shade of the trees (Al-Kharusi, 1995). The trees were numbered in replacement of bed numbers, and doctors would see and check these patients as well as the indoor patients.

The most commonly diagnosed medical problems at that time were anaemia, trachoma, malaria, tuberculosis and intestinal parasites. Inguinal hernias, Caesarian sections, circumcisions and orthopaedic cases were the most common surgical cases (Al-Kharusi, 1995). Al-Kharusi (1995) noted in her article that diabetes, heart diseases, gall bladder disease, and acute appendicitis were very rare in those days.

At present, Oman's health indicators have improved from the earlier years. For example, the life expectancy at birth increased from 76.1 in 2010 to be 76.6 in 2014 (life expectancy

in 1970 was only 40 years). Now, Oman's population life expectancy is considered among the highest in the world for +70 years. The crude death rates per 1000 population decreased from 3.1 in 2010 to be 2.9 in 2014 which demonstrates the reduction in the mortality rate that took place over these years, and implies that there has been an improvement in the health services provided for Omanis.

Also, the statistics show that the recorded total live births were ~ 83 thousands in 2014 compared to ~ 65 thousands in 2010. The recorded total death was 7.8 thousand in 2014 compared to 7.4 thousands in 2010. Also, Oman has achieved a very important thing in its recent history which is establishing, controlling and delivering a successful immunization program. Oman achieved at least 90% childhood immunization coverage, and it was one of the 12 countries that achieved the year 2000 target which was set by the "World Summit for Children 1990" (Ministry of Health – MOH, 2014). Also, the MOH was able to reduce the communicable diseases rates to 43 % in 2012. In 2008, the Oman World Health Survey (OWHS) was conducted study to assess Omani individuals' satisfaction with their health and their aspects of life using the World Health Organisation Quality of Life (WHOQoL) scoring tool. The survey reported that 82% of Omanis are satisfied with their quality of life (Ministry of Health – MOH, 2014).

Currently, the health sector in Oman faces number of challenges such as: having a small population with a high ratio of expatriates, which challenges the distribution and allocation of the health services while maintaining equity and access to health services, especially with continuously changing expatriate ratios and context; the difficult landscape and topography of Oman as huge areas of Oman, where some Omanis are scattered and live in a high rough mountains and barren valleys and this is a barrier to accessing health services; the high expectations and demands of the Omani population towards the health services in Oman which require improved service quality; the expectation of the international community for the health services in Oman to provide high quality health services, equity among people and good responsiveness for its stakeholders (Ministry of Health – MOH, 2014).

Accordingly, for the Oman's MOH to cope up with all the expected challenges, it attempted to visualize the future of the health services in Oman until the year 2050 and made a strategic plan called "The health vision 2050". The main aim of this vision is that "the Omani people live healthy and productive lives through establishing a well-organised,

equitable, efficient and responsive health system, grounded by social values of equity and social justice” (Ministry of Health – MOH, 2014).

The demographic analysis of the vision 2050 showed that the total population is predicted to be more than seven million by 2050. There will be an age shift where the elderly ratio will increase to be 13.1% compared to 10.7% in 2014. Also, the epidemiological profile of the country is rapidly shifting to an increase in non-communicable diseases (Ministry of Health – MOH, 2014). The evolution and development of the country have perhaps contributed to raising the prevalence of such risk factors among the Omani population as obesity and high cholesterol levels. For example the Ministry of Health (2014) reported that: 35.2% of Omanis were hypercholesterolemic, 32% had low-density lipoproteins, 29.5% are overweight, 24.1% are obese, 75% of hypertensive patients do not know about their high blood pressure, and 52% of diabetic patients do not know their increased blood sugar levels. The prevalence of diabetes has increased from 8.4% in 1991 to 13.2% in 2008. In Oman, the two known leading causes of hospital death were cardiovascular and neoplastic diseases (Ministry of Health – MOH, 2014).

Research is one of the most important visions the MOH is looking to improve. The MOH had identified research as an area of deficiency. Since 2001, the MOH incorporated research in the five-year health development plan, yet there is much work still to be done to embed the research culture in Oman. The country’s interest in research is represented in three main sites, first the Sultan Qaboos University (SQU), which has nine research centres; then the MOH which is central research centre; and recently the Research Council (called TRC) which is a national research model that provides an open research grant for eligible applicants, especially those who choose a research topic of a national priority. Currently, the national research priorities for MOH are for example, NCDs, road traffic accidents, molecular biology, and genetics.

Within the 2050 vision, the Ministry has developed sub-visions to provide a framework for the development of research in Oman. These sub-visions are:

- Vision 1: Availability and accessibility of reliable, relevant, up-to-date and timely health and health-related information ensured.
- Vision 2: Sustainable funding for health research and development ensured.
- Vision 3: Health research directed to identify priorities.

The Oman's MOH has to sustain a source of funding which will help in achieving all the vision planned by 2050. This sustainability is very challenging since the income of Oman is declining because of the reduction in the oil prices in the international market. Renal care is also one of the health services that struggling to sustain persistent fund to keep this important services running up to the golden standards and free of charge to enhance accessibility and equitability.

3.8 Conclusion

Since the 1970s and until the present, Oman as a country has achieved a lot of growth in political, economic, social, technological, legal and environmental areas. Politically Oman is a stable and peaceful country; continuing to follow the same approach will help the country and its people to grow and develop further.

Economically Oman is growing fast, but this is sometimes disturbed by any decline in the value of oil. So the country has to shift the income source from oil to non-oil because the oil resources will not sustain forever. Oman and its health sector have to be well prepared for any fluctuation in the economy, so the consumer at all times will maintain stability and satisfaction (Marmol, 2015). The Omani government and the health sector especially have to make critical observations on key economic indicators of the world, and consumption trends to amend their policies as needed (Marmol, 2015).

Oman's location is very important and having the Strait of Hormuz (shared with Iran) gives the country double importance as no sea entry can be made to the GCC or exit without crossing the Strait. Oman can make very good use of this Strait through the application of reasonable customs fees and taxes if access is to be made by foreigners. The administrative distribution of Oman to governorates make it easier for the governors and the authorities to manage the country more effectively. This distribution can be utilised further to develop strategic plans to develop the governorates and their people further.

The social status of the Omani community is good, and the rapport between families is still strong. Also, Omanis as a nation like to help and support others and they are known for their hospitality and decent behavior. Omanis are living densely in the capital, the north and the interior governorates. The authority may need to overlook this by providing a good ratio of services to proportion of the population wherever needed. Also, the capital is a very dense governorate and people from the other governorates travel to the capital for

work and sometimes decide to live in it. This issue needs in depth study to see the impact of this on the whole Omani community. For example, road traffic accidents are high in Oman, might be secondary to the frequent use of roads while travelling from governorates of Oman, espically from and to the capital.

The population of Oman is growing, and the country has to be prepared for this by increasing and improving the services especially of education and health. The education sector can work more on eradicating illiteracy and providing all kinds of education for Omanis. Education is an important tool used to increasing the health awarness among public espically toward preventing health problems such as kidney failure. The proportion of non-Omanis is currently high, and the country may need to study the impact of this on the system of Oman. Also, household income might be increased in a country with a high-income like Oman. Transportation and technologies are good and sufficient, but these can be developed further. The environment gets great attention from His Majesty and therefore it is well taken care of. The healthy water resources need to be maintained and made available for all people of Oman.

The health sector has achieved great things from 1970 until the present. The Vision 2050 is a very important document, and if implemented well it will upgrade the whole health system to a high-quality international system. Funding for health services needs to be secured and sustained. The MOH now is in a critical stage after setting the vision 2050. The low spending on health services in Oman needs to be increased, for example, in the UK spending has increased in the past 50 years from 3.4 % to 8.2 % (Appleby, 2013). The USA was reported as the highest spending country on health services at 17.6% (Ministry of Health – MOH, 2014). However, Oman compared to the UK, and some other countries is considered low in spending on health services. Oman is aiming to increase the total health expenditure by 8-10% by the year 2030 (Ministry of Health – MOH, 2014).

4 Methods of study one

4.1 Overview

The entry point to this research was the author's interest in kidney failure as a health problem affecting some people in Oman and around the world. Polit and Beck (2012) suggest that a personal interest in the topic is a "critical ingredient" in establishing good research. This interest prompted the author to review the existing literature to determine what was known and what was not yet known about kidney failure in Oman. The development of the conceptual framework for this research began from the point of the literature review. The initial reviewed literature addressed limitations in many knowledge aspects of kidney failure in Oman, more obviously a gap in the epidemiology of this disease. Disease epidemiology is an essential science that most of research pathways start with and build future research on its indications. As a result, the research questions were developed to focus on: (1) the development of RRT care in Oman from the outset, and identifying the main epidemiological variables of this health problem, and (2) identifying the socio-demographic characteristics, primary diagnosis, risk factors, co-morbidities, and death figures of kidney failure patients undergoing regular dialysis in Oman. These enquiries could perhaps be answered by reviewing the related literature, but there was no sufficient literature available at that early stage in 2013. Therefore, the primary aim was to develop a research study to gather some essential statistical data on kidney failure in Oman and make this available and accessible.

For this reason, this study consists of epidemiological research. However, for years, and by a number of researchers, epidemiology has been considered atheoretical, or a tool kit which helps science but does not theorize its science (Bhopal, 2008). On the other hand, Weed (2001) argued that epidemiology cannot be atheoretical due to the continued relevance of many theories, such as germ theory and epidemic theory, to the science of epidemiology. The major core theories of epidemiology reported by Weed (2001) were theories of disease occurrence and causation, theories of health, theories of probability, statistics and error, and theories of ethics.

Weed (2001) pointed out that theories of disease occurrence and causation are the most fitting theories for the science of epidemiology. The multi-factorial causation theory, which fits under disease occurrence and causation theory, is the most common framework used

by epidemiologists to understand the cause and effect relationship for diseases (Bhopal, 2008). The idea of this theory is that the disease occurs as a result of the interaction within the triangle of causation. The triangle of causation consists of the host, the agent, and the environment (Bhopal, 2008).

The triangle of causation model can be used to understand and analyse the causal relationships between kidney failure occurrence and the multi-factorial causes (Figure 4-1). The best design to test the cause and effect relationships between variables is randomised-control trials (Killam, 2013). However, the purpose of this study was not to examine cause and effect but to focus on creating the data related to kidney failure occurrence and its possible causes, not yet testing the relationship between kidney failure and its multi-factorial causes.

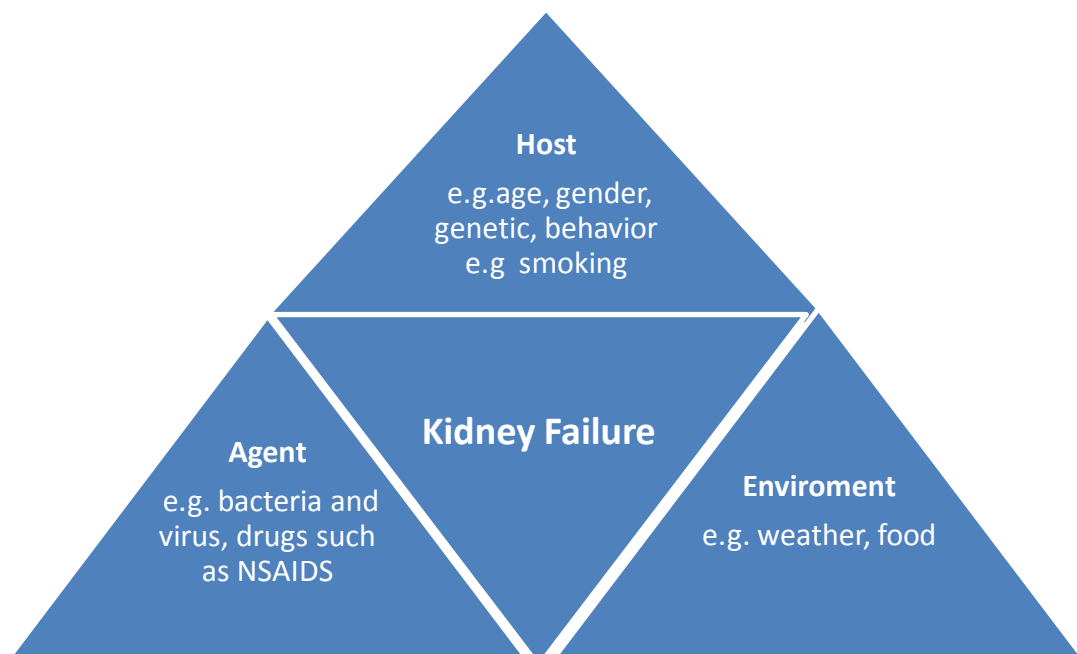


Figure 4-1 Kidney failure causation triangle (Bhopal, 2008)

4.2 Introduction

The clear conceptual stance, clear paradigm selection, and good determination of the research design are necessary steps toward successful answering of a research inquiry. In nursing research, the research inquiry has been conducted within two broad paradigms which are positivist paradigm and constructivist paradigm (Polit and Beck, 2014). The constructivist paradigm or naturalistic paradigm is mainly associated with qualitative research. This paradigm views reality as multiple and subjective, and follows the inductive process, interacts with those being researched to create findings, and seeks in-depth

understanding of the studied phenomenon (Polit and Beck, 2014). On the other hand, the positivist paradigm is mainly associated with the quantitative research. It follows the deductive process; the researcher is independent from those being researched and seeks the objective and quantifiable measurement of the studied phenomenon. Positivism embeds a scientific approach where the scientist uses a scientific-systematic approach to study a question of interest and importance. The data gathered by this study used a scientific-systematic approach as well by following a pre-determined plan (protocol). The data generated are usually numeric information, which results from some formal measurements and which are analyzed with statistical procedures (Polit and Beck, 2012). The assumption that guided the positivist paradigm of this study is ontologic which means in this case that kidney failure occurrence exists in reality and this phenomenon could be driven by natural causes (Polit and Beck, 2012)

The function of the research design is to answer one or more research questions. On the other hand, one research question can be answered by more than one type of research design (Katz et al., 2014). Research questions can be answered by numerical values (quantitative) where the intention is explanatory and deductive, or by narrative data (qualitative) where it is mainly exploratory and inductive (Claydon, 2015). Inductive and deductive paradigms are complementary and are both of importance in understanding a phenomenon (Polit and Beck, 2012). However, it is claimed that both paradigms are descriptive and that neither one is better than the other (Katz et al., 2014). It is the quality of the data gathered that gives the research study more or less credibility (Katz et al., 2014). The paradigm or design selected should serve the ultimate goal of generating a good quality of data that fills a knowledge gap (Polit and Beck, 2012). The selection of the design can depend on a number of criteria, such as the clinical topic (e.g. rare or common disease), cost, and availability and accessibility of the data (Katz et al., 2014).

The quantitative approach is selected because of the types of questions the quantitative research looks at. This research study posed some research questions related; mainly to describing the phenomenon of kidney failure in Oman; and to some extent exploring the risk factors and antecedents of this phenomenon. The quantitative description as stated by Polit and Beck (2012) and Polit and Hungler (1999) involve the prevalence, incidence, size and measurable attributes of a phenomenon (i.e. epidemiology). Description in quantitative research poses questions like; how prevalent is the phenomenon? How often does the phenomenon occur? And what are the characteristics of the phenomenon? (Polit and Beck,

2012; Polit and Hungler, 1999). These questions are exactly the same questions this study asked. Why this study asked these questions and perhaps no other questions was because the epidemiological data of kidney failure in Oman at the time this research proposed was scarce, and so providing this type of data can be the base for establishing a research base for this phenomenon (Hussanien and et al., 2012).

The data available on the Oman's treated kidney failure population at the time this project was planned, was limited. So to gather sufficient data about the studied health problem, an overall quantitative, mixed methods approach was selected. Also, qualitative data can generate a detailed amount of data, often more than quantitative, however it is less concise and serves a different purpose such as interpreting people experiences. It was anticipated that by conducting a quantitative study, the data generated would form the database which would potentially help in forming a renal registry for Oman, and in mapping the road for the future research needed in this field. Accordingly, this study was underpinned by quantitative research questions, where the research's major concepts were incidence, prevalence, death figures and characteristics of the treated kidney failure patients in Oman. These concepts are frequently used in epidemiological studies to describe, analyse, and interpret disease patterns (Bhopal, 2008).

Though the mixed approach of quantitative and qualitative combined is popular nowadays, however, the selection of the research approach always depends on the aims and research question chosen. Any researcher is advised to choose their research approach to the best way that her/his research enquires can be answered. Accordingly, the author chose the mixed quantitative approach because it was the best way seen to achieve the research aims. The author believes that at this stage there is a need to develop more objective and precise knowledge base, on kidney failure in Oman, which can be achieved by following the quantitative approach, though, the debate on the best research approach will continue. Some researchers support the mixed research approach and others support the entire separation of the quantitative approach from the qualitative approach (Hughes, 2014). In particular there are wider claims supporting the quantitative approach over the qualitative approach as the quantitative is seen as the most scientific and objective approach (Hughes, 2014). However both approaches have strengths and limitations. For example the quantitative approach is more précised and controlled but on the other hand it fails to interpret peoples experiences based on their uniqueness (Hughes, 2014). The qualitative

approach is more subjective but though it gives deeper insights on people experiences and differences which help to understand people's behaviours and actions (Hughs, 2014). Accordingly, it all depends on the type of scientific inquiry chosen. Ultimately, the selected research approach should satisfy the main goal of research which is discovering the true knowledge and finding the maximum possible facts to understand a phenomenon or a problem and thereafter find the solutions. Both research methodologies, quantitative and qualitative are important and complementary to each other at some instances.

4.3 The study's design

This first study was a secondary data analysis for the data obtained from the RRT register in Oman, and from the annual health reports (see appendix E-1, p.266), and published resources (see appendix E-2, p.267). The RRT register of Oman contains baseline statistics in relation to RRT population of Oman such as treatment modality, sex (see appendix E-3, p.268), regional distribution of RRT patients (see appendix E-3, p.268) annual death figures and causes of death.

This study measured the following; prevalence of Oman's RRT (1983-2015), incidence of Oman's RRT (1983-2015), death figures for Oman's RRT (1983-2015), and cost of dialysis treatment of Oman (1998-2015). The prevalence of Oman's RRT (1983-2015) is defined by this study as the number of kidney failure cases that reported in Oman's population in a whole annually since 1983 to 2015, and in the northern region of Oman population in particular (2014-2015) with major focus on dialysis statistics (as kidney transplantation statistics is not fully maintained and not fully reported on the same level of dialysis treatment in Oman). The incidence of Oman's RRT (1983-2015) is defined by this study as the number of new kidney failure cases that reported in Oman's population in a whole annually since 1983 to 2015, and in the northern region of Oman population in particular (2014-2015) with major focus on dialysis statistics. The death figures of Oman's RRT (1983-2015) is defined by this study as the number of death among RRT population that reported either annually or monthly since 1983 to 2015, and in the northern region of Oman population in particular (2014-2015) with a major focus on dialysis statistics. The mid-years population estimates were obtained from the National Center of Information and Statistics of Oman who publish the annual census of Oman on regular annual basis.

The variable of the cost of dialysis treatment of Oman is defined as the healthcare utilization in terms of dialysis sessions direct cost, which can be used as a proxy for disease burden of the healthcare system of Oman. There is no published data available on the direct or non-direct cost of RRT in Oman. However, this study attempted to calculate the cost of the dialysis sessions overall Oman because the statistics of total dialysis sessions were published by Oman's MOH webpage. The direct cost of a single dialysis session in the public sector was given by MOH as 49.8 Omani Rials (49.8 OMR = 104.7 GBP). The cost of dialysis sessions for the years 1983-1997 was not possible to calculate because the total number of dialysis sessions was not available. The cost calculated here is the direct cost of the dialysis treatment only and not taking into account the cost of staffing, equipment, and other non-direct costs. This information is needed by the policy makers to map the future policies based on field evidences. The evidence regarding the potential economic burden secondary to high expenditure is necessary to be disseminated to persuade the policy makers to allocate more fund or resources or to re-allocate resources in a way benefiting the public health (World Health Organisation- WHO, 2009). Mainly this part of the study is providing data on how much does the government pay for medical and may be for other direct expenses because of dialysis treatment. To measure more economical impact of RRT of society of Oman and health services, this will need further economic focused design which can be undertaken in the future.

This design is selected to achieve the following research objectives and answer the following research questions:

- ***Study one objectives***

1. To identify the major milestones of Oman's RRT development.
2. To identify the incidence, prevalence, death figures, cost and other significant data related to Oman's treated kidney failure population, such as causes of death.
3. To explore the status of publications related to kidney failure in Oman.

- ***Study one research questions***

1. In Oman, how have RRT developed from the outset?
2. What statistics are available in Oman for dialysis and kidney transplantation, i.e. incidence, prevalence, cost, diabetes mellitus (DM), and hypertension (HTN)*?
3. What pattern emerged from the gathered statistics?

4. On the national and international level, what information/studies are available concerning kidney failure, dialysis, and kidney transplantation in Oman since 1980?

*DM and HTN censuses were needed to identify if they are the major causes/risk factors leading to kidney failure in Oman.

4.4 The study settings

The data answering the research questions number one and four were gathered mainly from the Sultan Qaboos University Medical Library (SQUML), which is the biggest literature source for health sciences in Oman. This library was visited by the author in the capital to access and gather all local and national published data related to Oman's RRT population, from the 1980 until 2013. Some information about RRT development and publications were provided by the current nephrologist in charge of what will be called in this thesis as the central RDC. This central RDC is situated in the capital of Oman. In this RDC, all the routine and input data about the registered kidney failure patients and their RRT was gathered from all of Oman's RDCs and stored in the central RDC. This RDC was frequently visited by the author, and all the statistics available and data related to this study were gathered. Also, an online literature search was conducted to satisfy the research question number one.

Research question two data were gathered from the RRT register in Oman. According to Al-Ismaili et al. (2017), the RRT register data are retrieved in the central RDC, and the data are collected using USRDS 2728 survey form, which must be completed by the assigned nephrologists in all RDCs around the country once a person reached chronic kidney failure stage. All the data retrieved in the central RDC were checked and entered by nephrologists and rechecked by two other nephrology team members' using the computer software program Microsoft Access (Al-Ismaili et al., 2017). That process has been followed since 1998. The data from the previous years were collected and added retrospectively from patients' files from the only RDC that exist at that time in the capital (1983-1997) before the central RDC establishment in 1998 (Al-Ismaili et al., 2017). Most of the data obtained from the RRT register were on RRT populations' incidence, death figures, and causes of death, regional distribution of RRT population, modality distribution, diabetic nephrology figures and sex of patients. Also data on the incidence and

prevalence of the northern region of Oman were obtained from the individual four RDCs of the north. Data on prevalence and cost of dialysis of the national level were mainly obtained from the MOH health report (Figure 4-2).

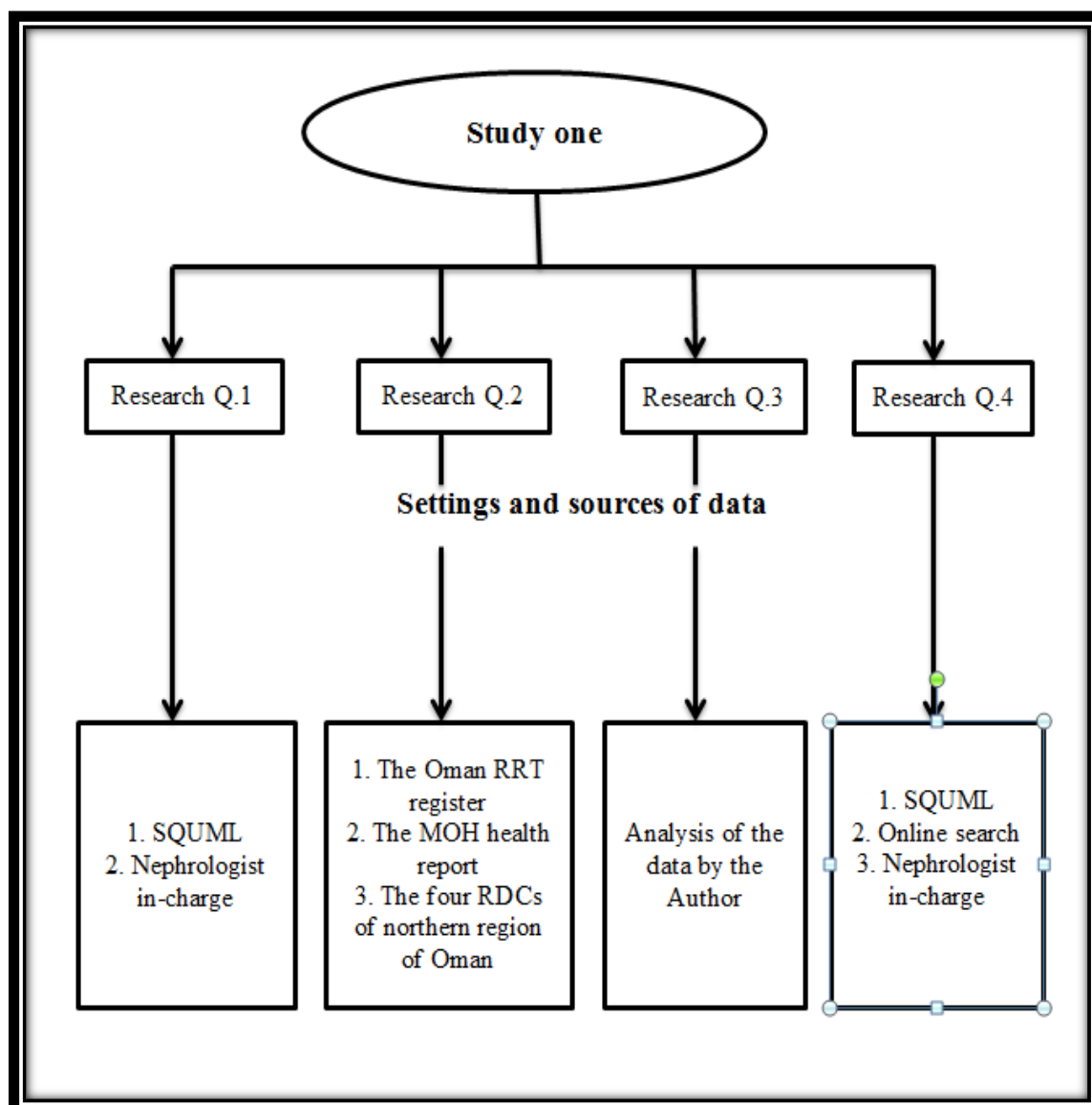


Figure 4-2 The original sources of data in relation to the research questions of study one

4.5 Study population and sample characteristics

The study population included all the treated kidney failure patients registered on Oman's RRT register of the central RDC and the other four RDCs the northern region of Oman since the register started in 1983, until 31st December 2015. The alive patients found registered on 4th November 2014; the day when the author first met with the nephrologist in charge of the central RDC, was 2,192 RRT patients. There was no physical contact with the sample, and also no individual or personal files were inspected in this study. The data

accessed were merely statistical data for the total RRT patients registered on Oman's RRT register since 1983 and until the end of 2015, and for the four RDCs from 1998 (the date of the oldest RDC establishment among the four targeted RDCs) to 2015. Also the northern region of Oman is administratively divided into two subdivisions which will be called subdivision 1 and subdivision 2. Each subdivision is served by two RDCs out of the four.

4.6 Ethical approval and considerations

Shaping and writing the protocol for this research took months to finalise. It was a requisite to have this protocol reviewed by different people, including two experts: two reviewers from the Research and Ethical Review and Approval Committee (RERAC) of the Oman's Ministry of Health. At the very end, University of Glasgow Ethics Committee had also approved the protocol.

The pilot study was conducted after the original protocol was reviewed by the ethical committees (see section 6.9, p.153). After the pilot study was completed, the original protocol was revised and a second ethical approval letter was obtained to permit the amendments in the revised protocol (see appendix A-3, p.246).

The subjects chosen for this pilot study were from the treated kidney failure population on dialysis, but from a different geographical area. This task was extremely helpful in identifying the study inadequacies and problems which were resolved before undertaking the main study (see section 6.9 on p.153).

Ethical permission was obtained from two ethical committees before starting the data collection. The first one was the "Research and Ethical Review and Approval Committee (RERAC)", Ministry of Health of Oman (see appendix A-1 on p.244). The second one was from the ethical committee of the University of Glasgow (see Appendix A-2 on p.245). The original protocol was revised by the ethical committees after the pilot study was conducted and a second ethical approval letter was obtained to permit the amendments in the revised protocol (see Appendix A-3 on p.246).

However, all the data obtained from Oman's RRT register were received anonymously from the central RDC nephrologist in charge. For this study, all the data obtained were

largely statistical numerals; no names and no addresses or other personal identification was accessed. Also, all names of places and people (if used) are anonymised as needed in this thesis to maintain an objective stance in viewing and analysing these study data. However the historical data of places and pioneers of the RRT service in Oman was not usually anonymised, to preserve the credits of these pioneers' achievements.

All kinds of research which involve humans have to adhere to the ethical rules, and have to be reviewed to ensure that the research participants are safeguarded, and their rights are protected (Polit and Beck, 2012). The first comprehensive consideration of medical ethics was published in 1803 by British physician Thomas Percival, followed by the American Medical Association's first code of ethics in 1847 (Beauchamp and Childress, 2013). In 1964, the World Medical Association developed the Declaration of Helsinki to legalise the ethics of medical practice and research involving human subjects (World Medical Association, 2016). The Declaration was amended ten times, from 1964 until the last amendments in 2013 (World Medical Association, 2016). The general ethical principles emphasised by this Declaration are to ensure respect for all human subjects, protect their health and rights, protect their life, health, dignity, integrity, right to self-determination, privacy, and confidentiality of personal information, and to maintain ethical standards overall (World Medical Association, 2016). Biomedical ethics rely on four major moral principles which are: 1) respect for autonomy, 2) nonmaleficence, 3) beneficence, and 4) justice (Beauchamp and Childress, 2013).

Respect for autonomy means respecting that a person has the right to make their own choices and actions depending on their own values and beliefs (Beauchamp and Childress, 2013). The participants' autonomy in this research were respected and maintained. In instances when the participant was incompetent, for example children with Down syndrome, the author approached the person authorised to make decisions on behalf of that participant (e.g. the husband or parents).

The principle of nonmaleficence means not causing any harm to others (Beauchamp and Childress, 2013). This research had no interventions, besides that most of the participants were surveyed in hospital settings where all preparations for first aid and emergencies were in place. Also, the author, in consideration of the patients' sickness, ensured that the interviews lasted for average of 15-20 minutes and no longer than 45 minutes.

Beneficence means helping and contributing to the welfare of others (Beauchamp and Childress, 2013). In this research, there was no direct benefit gained by participants, such as rewards. However, the patients gained by contributing to the data for this research, and may gain later benefits such as improved services delivered to them in consequence of this research being conducted and published.

The principle of justice means being fair and equitable in providing care for all individuals (Beauchamp and Childress, 2013). All participants in this research were treated in a fair and equitable manner.

In the UK, the government also acts to ensure the right processing of information relating to individuals by enforcing the Data Protection Act 1998. This acts and legislation regulates the process of obtaining, holding, use or disclosure of individuals' information (The National Archives, 2016). This research complies with all ethical standards and data protection acts.

Ethics, however, is involved in every single step in both research and life as well. Researchers should be aware of the ethical dilemmas that can be faced at any step in conducting research. The author should be able to use all the acts and legalisation in place to deal with all kinds of ethical dilemma (LeCompte, 2015). The ability to balance the need for data without threat to the participants' rights should also be demonstrated by the researcher in all instances (Cohen et al, 2011).

4.7 Data collection procedure

The collected data were accessed by submitting the ethical approval letter of Oman's MOH with a written request outlining the data desired for collection. The letters were handed to the nephrologist in charge of the central RDC. Also, similar request letters were given to the head of the other four RDCs in the northern region of Oman. The letters requested for the following data: the statistics of incidence, prevalence, death figures of dialysis sub-population, kidney transplantation statistics, statistics of kidney failure patients who had DM or/and HTN prior RRT; causes of death of treated kidney failure patients; distribution of kidney failure patients in Oman; any publications on Oman's RRT population; and a summary about nephrology service development in Oman. Most of the data were collected after several meetings and communications with the nephrologist in charge of the central

RDC who was cooperative and provided the necessary data as available. The data gathered from the other four RDCs were precisely about the development of each individual RDC since the commencement of that RDC, their incidence and prevalence, and it was collected simultaneously with the cross-sectional study data while visiting these RDCs.

Moreover, the author visited the medical library of the Sultan Qaboos University and inspected the national and local publications and records relevant to the Oman's kidney failure, by doing a manual search through the Oman Medical Journal (OMJ), the main scientific journal publishing medical and healthcare research in Oman. Thereafter, all the relevant information found related to kidney failure in Oman was extracted, copied and compiled. Also, the annual health records of the MOH of Oman were manually inspected when they were not available electronically. This annual record was very helpful in tracking the prevalence and cost of dialysis patients since 1998 (first published annual report found by the author) until 2015 (the last published record until the last point of inspection).

4.7.1 Statistical analysis

The data from this design were analysed statistically by the author using Excel spreadsheet. The numerical variables for example prevalence figures were entered and then were plotted on bar graphs to draw trends and conclusions. The incidence, prevalence and mortality rate were calculated by dividing, for example, the prevalence value for a period by the population at risk value, and then multiplying by 100,000 population to identify the rate of kidney failure cases per 100,000 population, or multiplying by 1,000,000 if the rate required is per million population (pmp). Most of the population values used in this study are for Omani populations or general population as indicated. The formula used to calculate the annual direct cost was by multiplying the dialysis session direct expense (49.8 OMR), times the total number of dialysis sessions performed per calendar year per Oman.

5 Results of study one

5.1 Overview

This section reports the results of the study one which is mainly a descriptive epidemiology of the RRT population of Oman. This study highlight the main developments of Oman's RRT and main epidemiological statistics (1980-2015), and status of Oman's RRT publishing. This chapter is structured under four main sections, namely: The main developments of Oman's RRT (1980-2015), the main statistics about Oman's RRT population, kidney transplantation in Oman, and publications on Oman's RRT population.

5.2 The main developments of Oman's RRT (1980-2015)

Nephrology care was launched in the modern world in the 1950s-1960s, and after two or three decades, Muscat arrived on the international scene of nephrology (Woods and Prabhakar, 1985; Thomas, 2014). Nephrology care started in Oman in the early 1980s as a result of great efforts from the MOH of Oman and some non-Omani nephrology physician pioneers.

The first RRT care started in Oman was peritoneal dialysis in April 1980 by Dr. Sayyed Laiq who was a consultant in general internal medicine. Thereafter, general nephrology services were made available in the capital in August 1982 (Woods and Prabhakar, 1985). This service offered one nephrology Out Patient Department (OPD), a hypertension referral clinic, paediatric nephrology and kidney transplantation on a weekly basis in Al-Nahda Hospital (an old hospital situated in the capital, Muscat, and which still exists). It was an active OPD with an average patient load of 300 patients (Woods and Prabhakar, 1985). Between 1980 -1983, peritoneal dialysis was still conducted in Oman but for only acute kidney failure patients.

On March 12th, 1983, the first dialysis centre opened in Al-Nahda Hospital with seven machines for haemodialysis and serving 35 patients (Woods and Prabhakar, 1985; Al-Maymmani, 2014). The patients who were on dialysis outside the country in places such as Bombay, India were brought gradually to Oman to resume their dialysis in the Al-Nahda

Renal Dialysis Centre (Al-Maymmani, 2014-2016). Al-Nahda Renal Dialysis Centre played the role required at that time for teaching and training nephrology staff. This centre was part of a program developed by the MOH at that time. This program was called Chronic Renal Failure Program (CRFP), and aimed to treat Omani patients in their country instead of taking them abroad (Woods and Prabhakar, 1985). Moreover, a plan was made by the MOH to establish further dialysis centres in the interior places of Oman (Woods and Prabhakar, 1985).

Woods and Prabhakar (1985) reported 113 patients (i.e. 108 Omani patients and five non-Omanis) who were diagnosed with kidney failure and started dialysis from March 1983 to July 1985. They reported 53.4% males to 46.6% females, but if the non-Omani patients were excluded then there were slightly more Omani female patients compared to Omani males.

The death percentage among this population at that time was 17.7% (of the whole treated kidney failure population in Oman including acute kidney failure). Ten point five percent of kidney failure patients were lost to follow-up which means they had been diagnosed with chronic kidney failure but failed to appear for dialysis at the Al-Nahda Renal Dialysis Centre before July 1985, but presumed not necessarily dead (Woods and Prabhakar, 1985).

In 1992, continuous ambulatory peritoneal dialysis was introduced, and the first patient was dialyzed in the Royal Hospital at Muscat (Al-Marhuby, 1998), a large tertiary teaching hospital where all specialties and subspecialties are offered for all of the Omani's citizens (Ministry of Health, Royal Hospital page, 2014). However, the peritoneal dialysis structured program started in 1993 in Oman.

The first remote RDC outside the capital and the second in Oman was launched in the northern region of Oman in September 1991 (Al-Maymmani, 2014-2016). On the 4th April 1992, a third RDC was opened in the southern region of Oman (Al-Maymmani, 2014-2016). The central RDC was launched on 29th January 1998 in the capital of Oman, Muscat. This RDC is managed by a nephrology team led by a nephrology physician and assisted by a nephrology nurse. The creation and maintenance of the Oman's RRT register was a personal effort from Dr. Hamood Al-Marhubi who was the nephrologist in charge of the central RDC and at present he is retired. He was the data keeper for the treated kidney failure population in Oman for around three decades, and he was the one who transferred the hand-written data about this population from the Al-Nahda Renal Dialysis Centre (the

previous central RDC) to the current central RDC (Al-Maymmani, 2014-2016). The effort was continued after Dr. Hamood's retirement by Dr. Yaqoob Al-Maymmani, who is the current nephrologist in charge of the central RDC. Credit should be given to these people for securely retrieving these fundamental data for all these years. The data were stored in an electronic form in a central computer in the central RDC. The data cannot be accessed by any person except the nephrologist in charge and his delegate. These data were never used or published prior to 2014 except on a small scale for the annual health reports and once within a study conducted in 2004-2005 (the study called "frequency of diagnosed hypertension, proteinuria, haematuria, urinary tract infection impaired kidney function and their geographical distribution amongst different age group of individuals in Sultanate of Oman" – principle author Dr. Hamood Al-Marhuby, 2004-2005). This study also was never published in an electronic form but only in a paper form and disseminated only among the people concerned.

The annual health report published by the Oman's MOH for the year 2004 showed that Oman had 13 RDCs (Ministry of Health- MOH, 2004). These RDCs had a combined total of 113 dialysis stations and served around 558 patients by the end of December 2003 (Ministry of Health- MOH, 2004). These dialysis centres increased gradually to 15 RDCs by the end of 2005 (Ministry of Health- MOH, 2006). The 15 RDCs had a combined total of 158 dialysis stations and treated around 618 patients per annum. The ministry closed one RDC in 2005, but there were two RDCs established in a replacement during the same period. By 2008, the MOH was successfully running 17 RDCs that had a combined total of 169 dialysis stations serving around 737 patients on dialysis (Ministry of Health- MOH, 2009). By the end of 2015, the MOH owned 18 RDCs with 217 dialysis stations covering 1439 patients on dialysis per annum per total population (Ministry of Health- MOH, 2016). Between 2012 and until 2015 the MOH did not increase the number of RDCs (Figure 5-1 and Figure 5-2) but increased the number of dialysis stations in some of the existing RDCs such as the central RDC which started with 28 dialysis stations and increased to be 42 dialysis stations by the end of 2015.

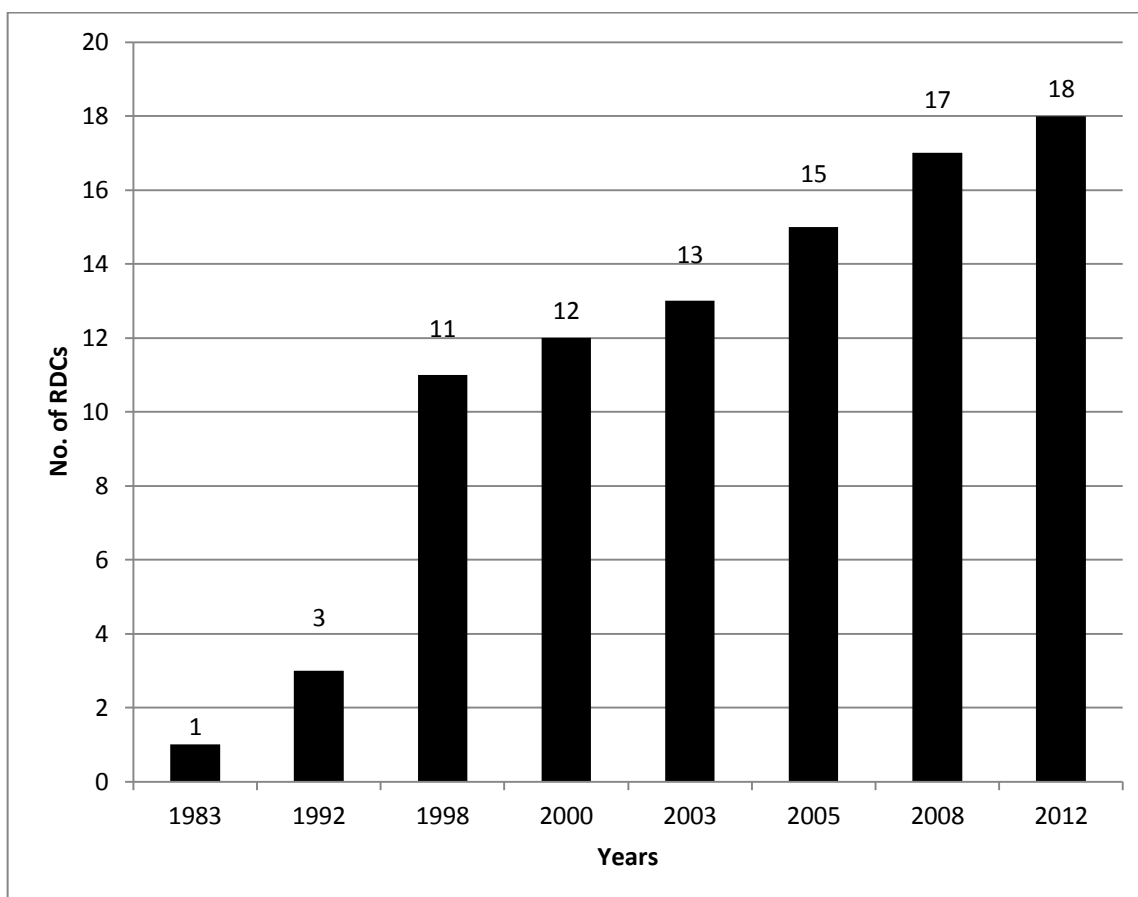


Figure 5-1 The growth in number of RDCs in Oman

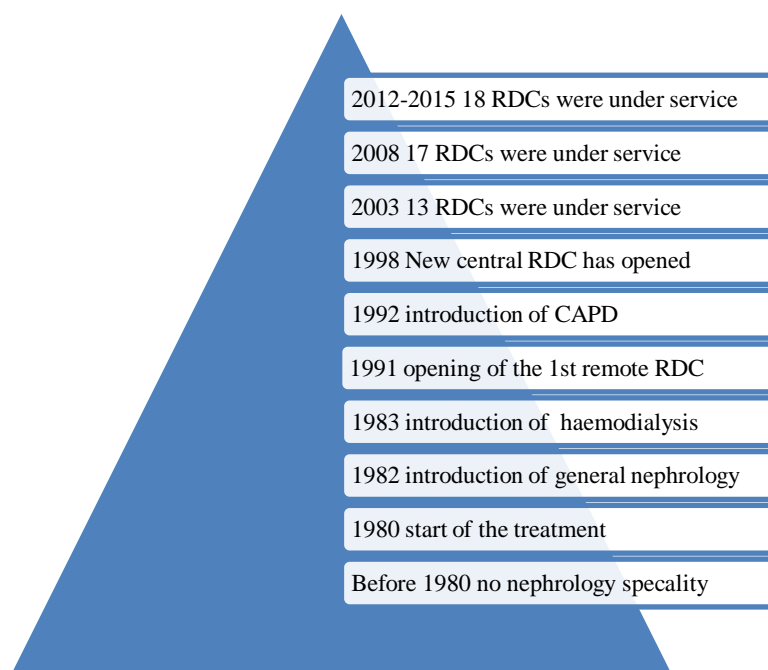


Figure 5-2 The increase in dialysis treatment capacity in Oman 1980-2015

5.3 Main statistics about Oman's RRT population

5.3.1 Prevalence of Oman's RRT (1983-2015)

Although the dialysis treatment prevalence from 1983-1997 was not available on the Oman's MOH website and could not be found by hand searching in the grey literature, the prevalence from 1998-2003 was found by hand searching in the hard copies of the Oman's MOH annual reports, and those from 2004-2015 were available on the MOH website (www.moh.gov.om - Ministry of Health- MOH, 2004 - 2016). Also, the prevalence for 1983 and 1985 was collected from an article published in the Oman Medical Journal in 1985 (Woods and Prabhakar, 1985).

The total number of patients registered on the Oman's RRT register of the central RDC from 1983 until 2010 was 3,524 kidney failure patients (including non-Omanis) distributed for the following treatments' cohorts; haemodialysis, 2,328 patients (66%); kidney transplant, 1,144 patients (32.5%); peritoneal dialysis, 52 patients (1.5%). There were no data provided for how many of each gender were in each of the treatment cohorts, but overall, males constituted 1,904 patients (54%), and females were 1,620 patients (46%). However, of the 3,524 (100%) registered patients between 1983 -2010, only 1,818 (51.6%) patients were alive in 2010; 1,542 patients (43.7%) had died, and 164 patients (4.7%) were lost to follow-up or could not be traced because they did not come back for their dialysis and did not provide any information on their treatment outcomes. By the end of December 2013, the total alive RRT patients registered on the Oman's RRT register were 2,069 alive patients distributed as 1117 dialysis patients (54%) and 952 (46 %) kidney transplanted patients. Accordingly, live patients increased 13.8% in between 2010-2013 with mean annual increase of 83.6 patients per year. The last RRT prevalence the author was able to record was the point prevalence on 4th November 2014 when the author first visited the central RDC for data collection. The point prevalence was 4,228 (100%) deceased and alive patients, however, the alive were 2,192 (42.3%) RRT patients across the country. As a result, there were 123 kidney failure patients case were added to the prevalence from end of 2013 to the 4th of November 2014. The 2,192 RRT patients were distributed in three main cohorts. The haemodialysis cohort had 1,161 patients (52.9%), the peritoneal dialysis cohort had 76 patients (3.5%), and the cohort who had functional kidney transplants had 955 patients (43.6% - Table 5-1). The number of male patients was higher in all cohorts except in the PD cohort (Table 5-1). The total population of Oman on 2014 was 3.993 millions in general or 2.261 million Omani. According to the previous statistics, the

prevalence rate is 549 pmp in 2014 if calculated across total population or 969.5 pmp if calculated across Omani population only.

Table 5-1 Oman's RRT population distribution across treatment cohorts on 4th November 2014

Variable	Males <i>n</i> (%)	Females <i>n</i> (%)	Total <i>n</i> (%)
Haemodialysis cohort	636(29%)	525(23.9%)	1,161(52.9%)
Peritoneal dialysis cohort	34(1.6%)	42(1.9%)	76(3.5%)
Kidney transplantation cohort	556(25.4%)	399(18.2%)	955(43.6%)
Total	1,226 (56%)	966(44%)	2,192(100%)

○ **Prevalence of Oman's dialysis treatment (1983-2015)**

The prevalence statistics from 1998-2015 showed an overall increase in dialysis treatment in Oman. The dialysis sub-population increased from 35 patients in 1983 to 1,439 patients in 2015. The available prevalence of dialysis treatment in the years 1983-2015 in Oman is illustrated in Figure 5-3. The mean prevalence for all years was 724.9 dialysis treatments (i.e. patients) per annum. The overall trend showed an increase in dialysis treatment prevalence over the years with slight dips in years 2003, 2005 and 2006 (Figure 5-3).

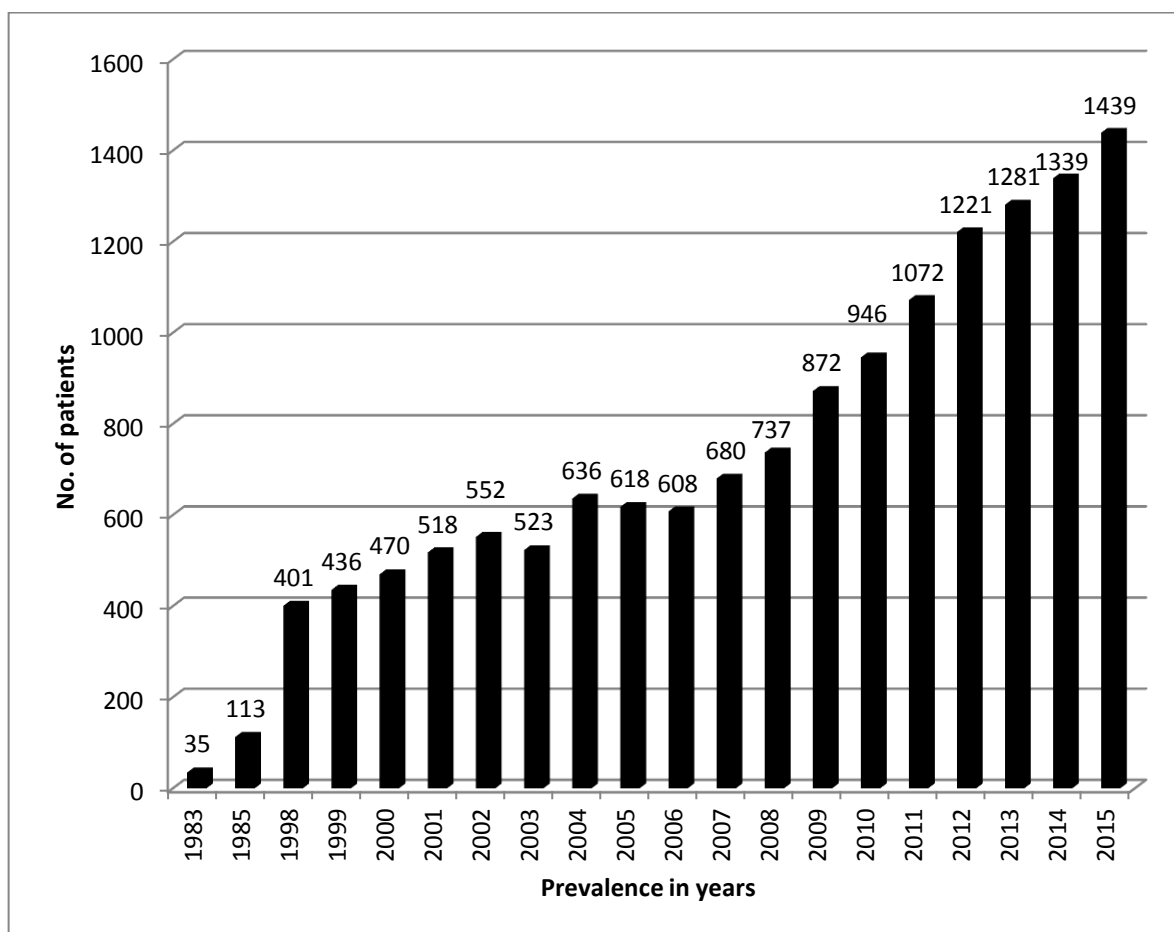


Figure 5-3 Prevalence of dialysis treatment in Oman (1983-2015)

It was possible to calculate the prevalence rate for dialysis treatment as the estimated census for Omani population and total population at risk was available for the years 1986 and onward. However, the prevalence for the years 2003 and 2013 were selected and calculated to the last available census of 2015 (Table 5-2). This prevalence rate was calculated across two values the total population and the Omani population in order to describe if there is significant differences between the two values.

Table 5-2 Prevalence rates for dialysis treated patients in certain years

Year	Prevalence	Total Pop.	PR of Total Pop.	Omani pop.	PR of Omani Pop.
2003	523	2,341,000	22.3/100,000	1,782,000	29.3/100,000
2013	1281	3,855,000	33.2/100,000	2,172,000	59/100,000
2015	1,439	4,159,000	34.6/100,000	2,345,000	61.4/100,000

Pop., population; PR, prevalence rate

- **Prevalence of RRT treatment across Oman's governorates**

Woods and Prabhakar (1985) reported that from March 1983 to July 1985, patients travelled from all parts of Oman to attend the dialysis sessions in the only centre of dialysis in the Al-Nahda Hospital, and that more than 50% of these patients were from the capital and in the northern region of Oman (Woods and Prabhakar, 1985). The distance between the capital and the nearest point in the northern region of Oman is around 200 km. The remaining 40% of the dialysis sub-population came from the rest of the governorates (regions) of Oman (Figure 5-4).

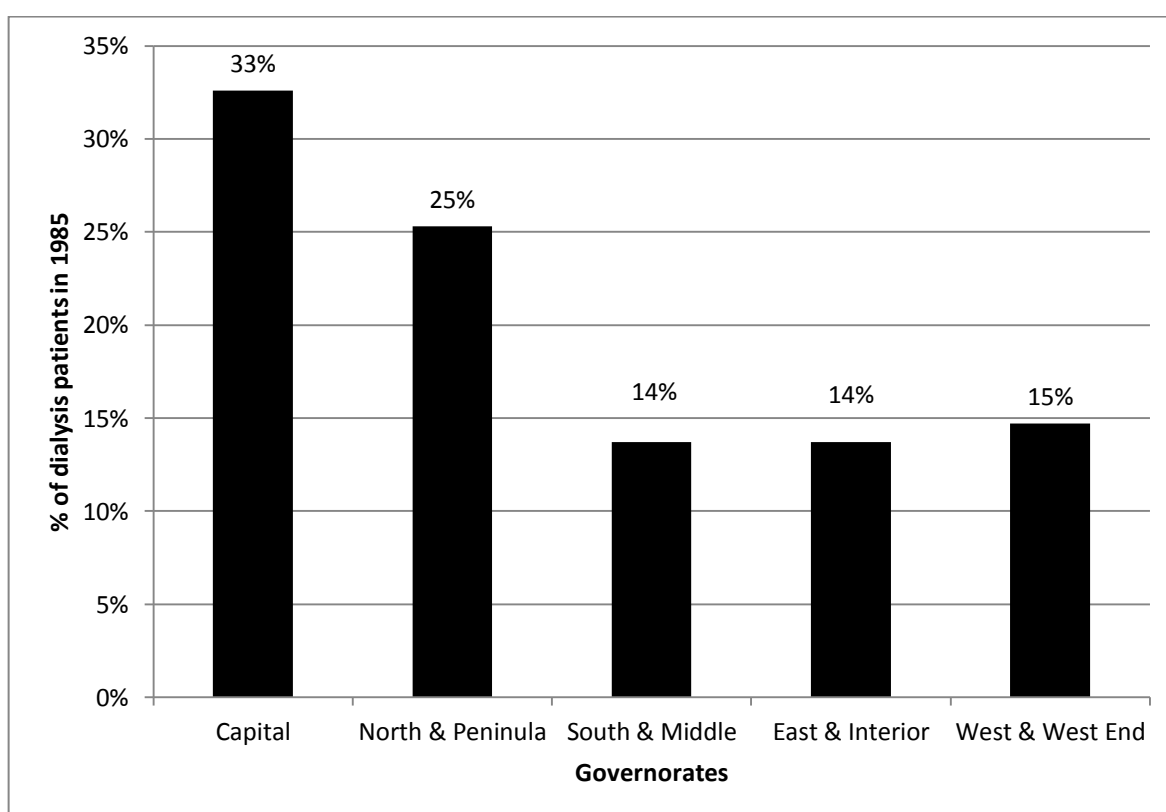


Figure 5-4 Distribution of the dialysis sub-population in 1983-1985 across Oman's main governorates

© Data from Woods and Prabhakar, 1985

According to Oman's RRT register, the 3,524 RRT patients registered in 2010 were distributed between nine main governorates of Oman, the highest in the capital ($n = 985 = 28\%$) and the lowest in the middle governorate ($n = 6 = 0.2\%$ - Figure 5-5), also 70 patients (2%) had no identified residential area.

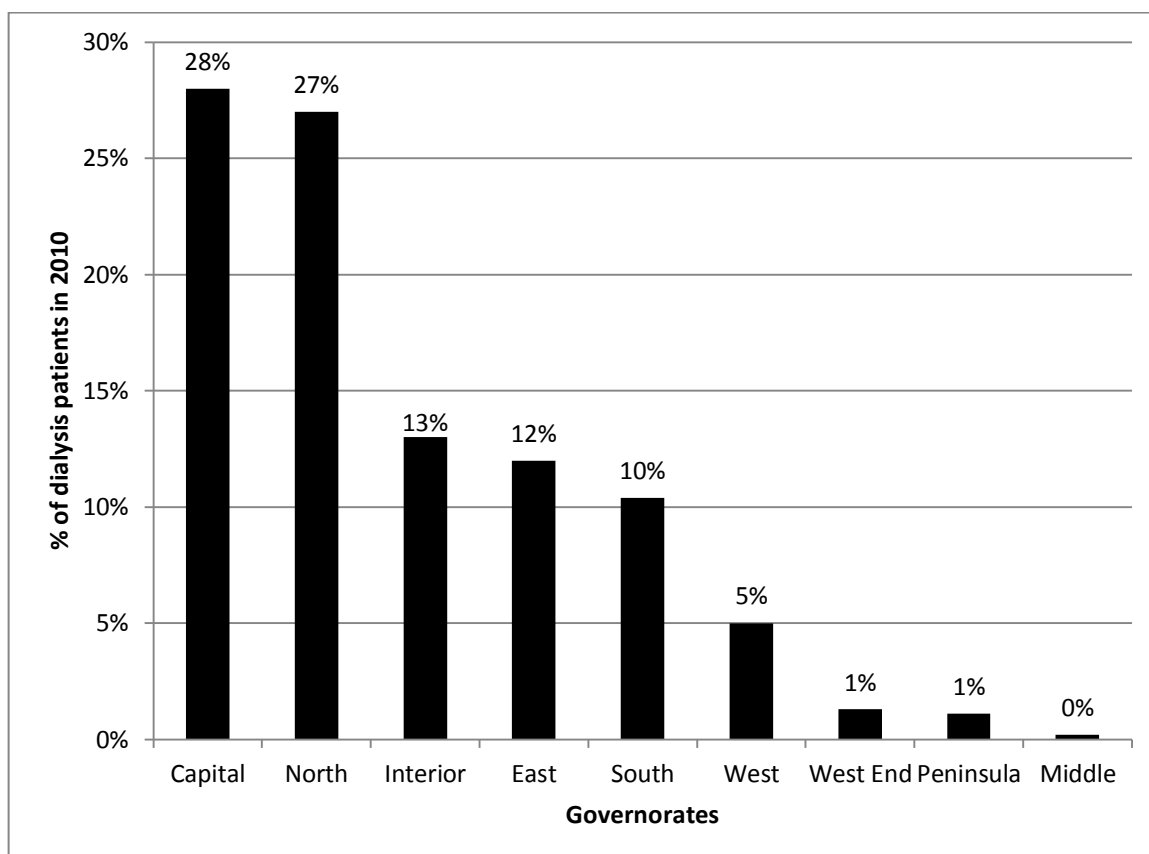


Figure 5-5 Distribution of RRT populations across Oman's governorates in 2010

(Note: 179 patients were recorded as unknown diagnosis, and therefore they are not included in this figure).

The Oman's RRT register had a record of all RRT patients treated since the start of RRT in Oman. Therefore the register recorded 4,228 treated kidney failure patients (deceased and alive together) who underwent RRT between 1983 and 4th November 2014. These 4,228 RRT patients were distributed among the governorates of Oman as the highest in the capital ($n = 1,296$ RRT patients = 30%), then the north ($n = 1,039$ RRT patients = 25%), and the lowest in the middle region ($n = 7$ RRT patients = 0.2% – Figure 5-6). Also, there were 67 (1.7%) RRT patients with no identified residential address.

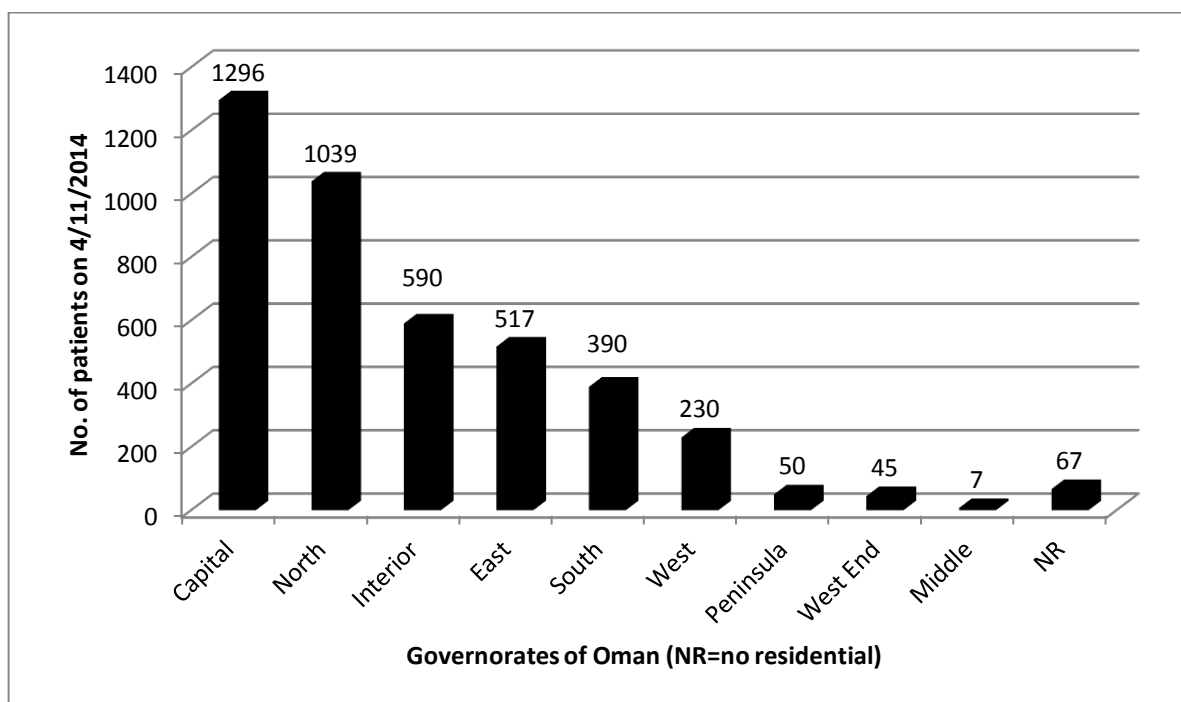


Figure 5-6 RRT patients' distribution across governorates on 4th November 2014

The prevalence rate of dialysis treatment across governorates was possible to calculate because the census of the Omani population and the total population at risk across governorates was available, and also governorates' prevalence figures of dialysis treated patients were available. The prevalence of dialysis treatment across governorates is given here for two years only, which are 2010 and 2015, to allow for a comparison. In 2010, the highest prevalence rate for dialysis treatment was in the capital at 71.3 dialysis patients per 100,000 Omani populations and at 37.4 dialysis patients per 100,000 total populations. The lowest rate was in the west at 30.3 dialysis patients per 100,000 Omani population, and at 23.7 dialysis patients per 100,000 total populations (Table 5-3). In 2015, the highest prevalence was in the west end at 99 dialysis patients per 100,000 Omani population, and at 49.5 per 100,000 total population. The lowest prevalence was in the north at 46.8 dialysis patients per 100,000 Omani populations, but per total population it was in the capital at 30 dialysis patients per 100,000 total populations (Table 5-3).

Table 5-3 Prevalence of dialysis treated patients across governorates of Oman for 2010 & 2015

Year Governorate	Omani pop.	Actual Prev.	Per 100,000 Omani pop.	Per 100,000 pop.	Total
2010					
Capital	407,006	290	71.3	37.4	
South	164,073	92	56.1	36.8	
Middle	19,043	-	50.2*	31.5	
Peninsula	21,898	10	45.7	31.8	
North	620,950	266	42.8	34.4	
Interior	269,069	111	41.3	34	
East	293,394	119	40.6	34	
West	118,877	36	30.3	23.7	
West E	43,026	22	51.1	30.2	
2015					
Capital	487,592	384	78.8	30	
South	196,560	159	80.9	41.2	
Middle	22,814	-	72.5*	37.2	
Peninsula	26,232	17	64.8	41.6	
North	743,920	348	46.8	32.9	
Interior	322,358	201	62.4	48.2	
East	351,506	205	58.3	39	
West	142,421	74	52	38.6	
West E	51,543	51	99	49.5	
PR prevalence rate; pop., population; Prev., prevalence; *the prevalence of the middle governorate was never published by MOH and therefore it is most likely that its prevalence is counted within the southern governorate's prevalence; West E, west end					

○ **Prevalence of dialysis treatment in the four RDCs of the northern region of Oman (1998-2013)**

RDC1 was established in 2008; therefore, the prevalence data presented here are for the years 2008-2013. The dialysis treatment increased from 55 dialysis patients in 2008 to 124 patients in 2013; full years' statistics are illustrated in Table 5-4. RDC2 was established in 1995 and the prevalence was available for the years 1998 to 2013. Also, the prevalence of this RDC increased from 27 dialysis patients in 1998 to 47 in 2013 (Table 5-4). RDC3 was established in 1993; the prevalence reported was for the years 1998 to 2013, and it similarly increased from 40 dialysis patients in 1998 to 95 in 2013 (Table 5-4). RDC4 was established in 1997 and the prevalence reported for the years 1998-2013, the prevalence similarly increased from 30 dialysis patients in 1998 to 94 in 2013 (Table 5-4).

Table 5-4 Prevalence of dialysis treatment in the four RDCs of the northern region of Oman (1998-2013)

Prevalence in Year	RDC1 <i>n</i>	RDC2 <i>n</i>	RDC3 <i>N</i>	RDC4 <i>n</i>	Total <i>n</i>
1998	*NE	27	42	30	99
1999	NE	29	30	47	106
2000	NE	31	31	57	119
2001	NE	36	30	70	136
2002	NE	41	36	67	144
2003	NE	35	32	64	131
2004	NE	40	35	74	149
2005	NE	40	36	64	140
2006	NE	45	35	64	144
2007	NE	50	40	64	154
2008	55	28	45	69	197
2009	77	29	58	72	236
2010	95	31	61	79	266
2011	102	31	79	84	296
2012	114	39	69	114	336
2013	124	43	95	94	356
*NE, not established					

The overall cumulative prevalence figures for the three to four RDCs (2008-2013) are illustrated in Table 5-4; the overall prevalence in the four RDCs increased from 99 dialysis patients in 1998 to 356 dialysis patients in 2013 (Figure 5-7). The overall trend shows a 260% increase in the dialysis treatment prevalence across the four RDCs. However, there were some dips in 2003 and 2005.

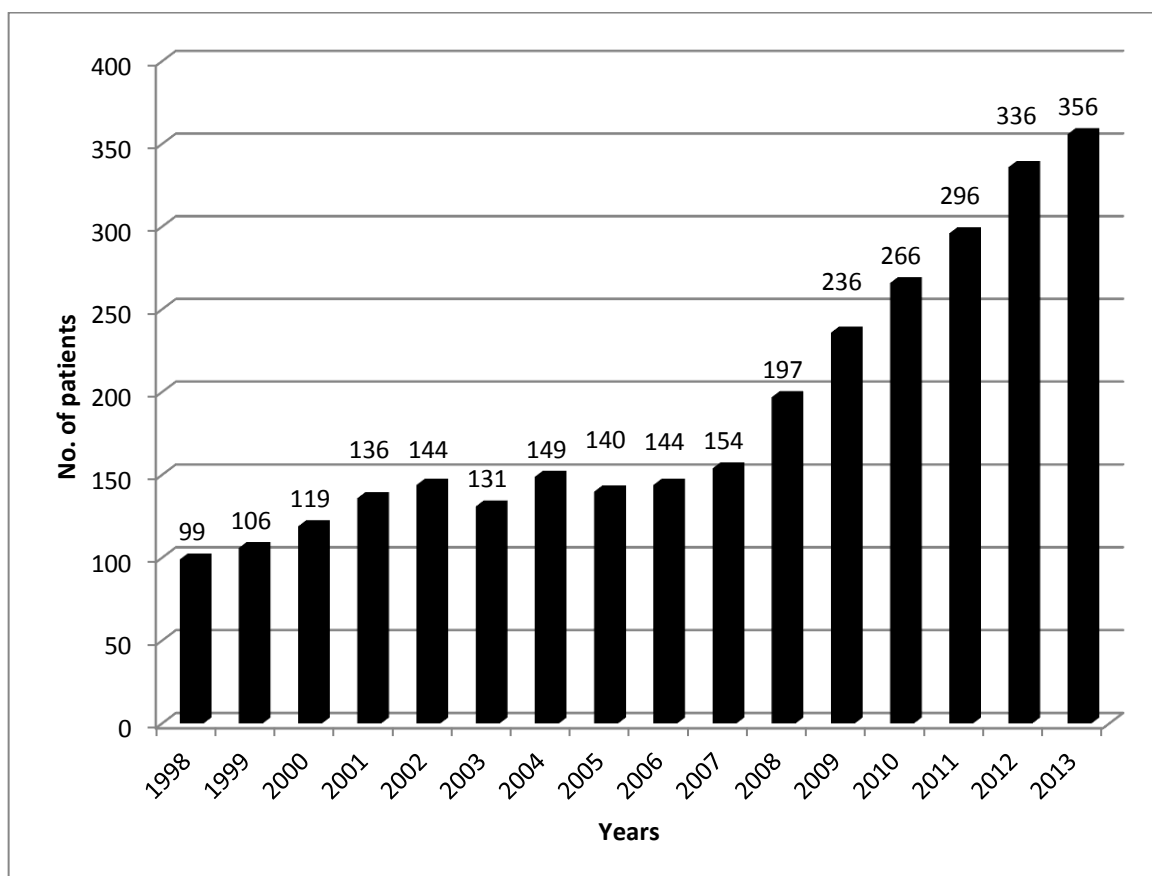


Figure 5-7 The overall prevalence of dialysis treatment in the four RDCs of the northern region of Oman (1998-2013)

○ **Prevalence of dialysis treatment in the four RDCs of the northern region of Oman at the time of data collection (2014-2015)**

At the time of data collection during October-November 2014, there were 341 (100%) Omani patients undergoing kidney dialysis treatment in the northern region of Oman. Specifically, there were 335 (98.2%) adult patients and six (1.8%) paediatric patients. In 2014, the Omani adult population of the northern region of Oman was ~395 thousands and the Omani paediatric population was ~322 thousands and total Omani population was ~717 thousands. Accordingly, the prevalence rate of adult patients on dialysis treatment in the northern region of Oman was 84.8/100,000 Omani adult population in November 2014. The prevalence rate of Omani paediatric patients on dialysis treatment in the northern region of Oman at the same period was 1.8/100,000 in November 2014. However, the overall prevalence of dialysis patients across the four RDCs in 2014 was 301 patients in January 2014 and 312 patients in 31st December 2014 (Table 5-5). This means that the overall prevalence rate for dialysis cohort across the four RDCs was 43.5/100,000 per total population of the northern region of Oman on 31st December 2014 (Table 5-5). According

to subdivisions, the prevalence rate for subdivision 1 was 61.7/100,000 and the prevalence rate for subdivision 2 was 39/100, 000.

Table 5-5 Prevalence of dialysis treatment across the four RDCs per month in 2014

Month in 2014	RDC1		RDC2		RDC3		RDC4		Total	
	<i>n</i>		<i>n</i>		<i>N</i>		<i>n</i>		<i>N</i>	
January	120	M(70)	47	M(26)	94	M(57)	40	M(21)	301	M(174)
		F(50)		F(21)		F(37)		F(19)		F(127)
February	118	M(69)	50	M(28)	94	M(57)	40	M(20)	302	M(174)
		F(49)		F(22)		F(37)		F(20)		F(128)
March	119	M(69)	51	M(27)	93	M(56)	101	M(49)	364	M(201)
		F(50)		F(24)		F(37)		F(52)		F(163)
April	119	M(69)	48	M(25)	90	M(53)	102	M(46)	359	M(193)
		F(50)		F(23)		F(37)		F(56)		F(166)
May	118	M(69)	48	M(25)	90	M(53)	98	M(46)	354	M(193)
		F(49)		F(23)		F(37)		F(52)		F(161)
June	119	M(68)	49	M(26)	89	M(52)	95	M(46)	352	M(192)
		F(51)		F(23)		F(37)		F(49)		F(160)
July	121	M(69)	51	M(28)	89	M(52)	101	M(46)	362	M(195)
		F(52)		F(23)		F(37)		F(55)		F(167)
August	123	M(69)	49	M(26)	88	M(51)	99	M(44)	359	M(190)
		F(54)		F(23)		F(37)		F(55)		F(169)
September	127	M(73)	50	M(27)	86	M(49)	99	M(44)	362	M(193)
		F(54)		F(23)		F(37)		F(55)		F(169)
October	128	M(74)	48	M(27)	86	M(49)	46	M(21)	308	M(171)
		F(54)		F(21)		F(37)		F(25)		F(137)
November	127	M(73)	48	M(27)	86	M(49)	49	M(22)	310	M(171)
		F(54)		F(21)		F(37)		F(27)		F(139)
December	126	M(72)	49	M(28)	85	M(48)	52	M(22)	312	M(170)
		F(54)		F(21)		F(37)		F(30)		F(142)

n, number; M, males; F, females

For the year 2015, the overall prevalence for the four RDCs had increased from 312 patients on 1st January 2015 to 332 patients on 31st December 2015 (Table 5-5). The overall prevalence rate per 100,000 populations calculated on 31st December 2015 was 43.5 patients in the northern region of Oman (the same prevalence rate as the year 2014). According to subdivisions of the northern region of Oman, the RDCs of subdivision 1 appeared to have a higher prevalence (64.6 cases in 100,000) compared to subdivision 2 (30.7 cases in 100,000).

Table 5-6 Prevalence of dialysis treatment across the four RDCs per month in 2015

Month in 2015	RDC1		RDC2		RDC3		RDC4		Total	
	<i>n</i>		<i>n</i>		<i>N</i>		<i>n</i>		<i>N</i>	
January	125	M(72)	47	M(28)	84	M(48)	56	M(26)	312	M(174)
		F(53)		F(19)		F(36)		F(30)		F(138)
February	126	M(72)	49	M(29)	83	M(48)	56	M(26)	314	M(175)
		F(54)		F(20)		F(35)		F(30)		F(139)
March	122	M(68)	51	M(29)	83	M(47)	42	M(22)	298	M(166)
		F(54)		F(22)		F(36)		F(20)		F(132)
April	122	M(69)	52	M(29)	86	M(49)	56	M(22)	316	M(169)
		F(53)		F(23)		F(37)		F(34)		F(147)
May	122	M(69)	53	M(29)	84	M(45)	47	M(22)	306	M(165)
		F(53)		F(24)		F(39)		F(25)		F(141)
June	123	M(70)	51	M(28)	86	M(45)	46	M(25)	306	M(168)
		F(53)		F(23)		F(41)		F(21)		F(138)
July	122	M(68)	49	M(26)	88	M(47)	60	M(25)	319	M(166)
		F(54)		F(23)		F(41)		F(35)		F(153)
August	123	M(68)	49	M(27)	86	M(47)	59	M(31)	317	M(173)
		F(55)		F(22)		F(39)		F(28)		F(144)
September	124	M(68)	50	M(29)	87	M(48)	53	M(29)	314	M(174)
		F(56)		F(21)		F(39)		F(24)		F(140)
October	124	M(68)	52	M(30)	88	M(48)	60	M(31)	324	M(177)
		F(56)		F(22)		F(40)		F(29)		F(147)
November	123	M(68)	56	M(30)	87	M(48)	47	M(20)	313	M(166)
		F(55)		F(26)		F(39)		F(27)		F(147)
December	124	M(70)	58	M(30)	87	M(48)	63	M(25)	332	M(173)
		F(54)		F(28)		F(39)		F(38)		F(159)

n, number; M, males; F, females

The figure for male patients appeared higher ($n = 170 = 54.5\%$) when compared to females ($n = 142 = 45.5\%$) on December 2014, and relatively the same figures on December 2015, males ($n = 173 = 52\%$) vs. females ($n = 159 = 48\%$). The statistics of patients' distribution according to the dialysis modality were as follows: out of the 335 dialysis adult patients, there were six patients (1.8%) undertaking peritoneal dialysis and registered in RDC4, and 329 (98.2%) patients undertaking haemodialysis treatment in all renal dialysis centres.

5.3.2 Incidence of RRT treatment (1983-2015)

Statistics of the RRT incidence were available for the years 1983 to 2015. The new patients registered in 1983 were 34 patients, in 1986 were 33, in 2013 were 168 and in 2015 were 230 patients per total population (Figure 5-8). The incidence of treated kidney failure patients across the years per Oman is displayed in Figure 5-8.

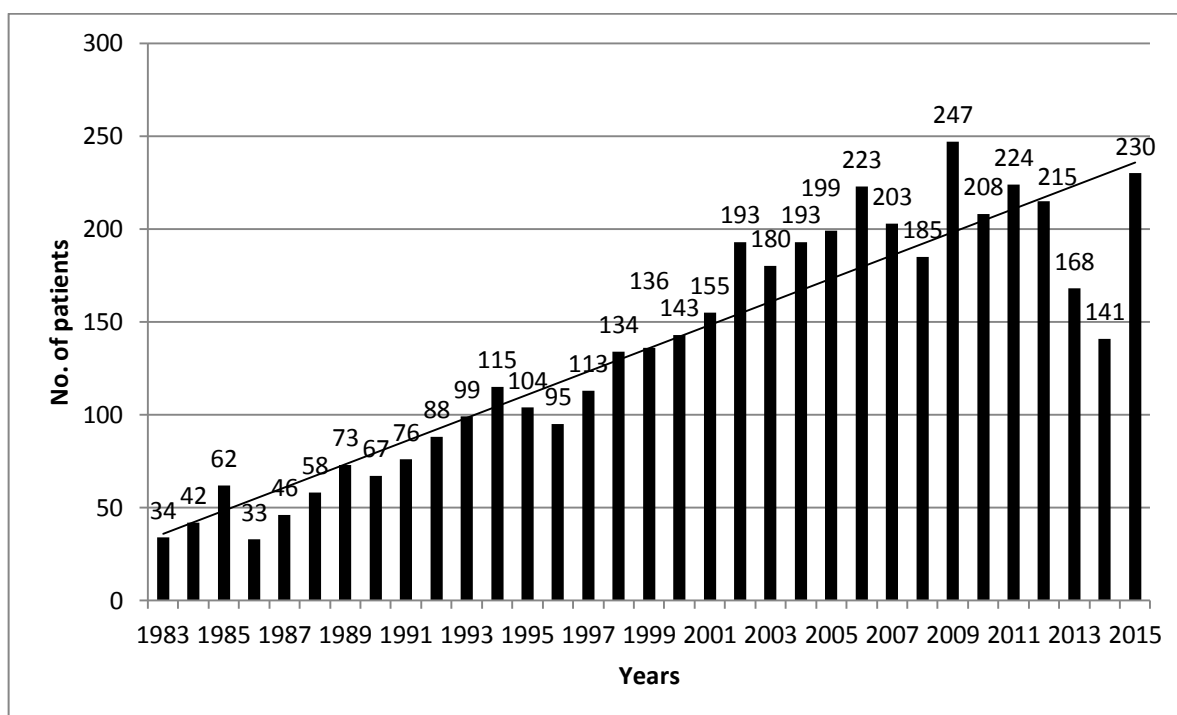


Figure 5-8 Incidence of RTT treatments in Oman (1983-2015)

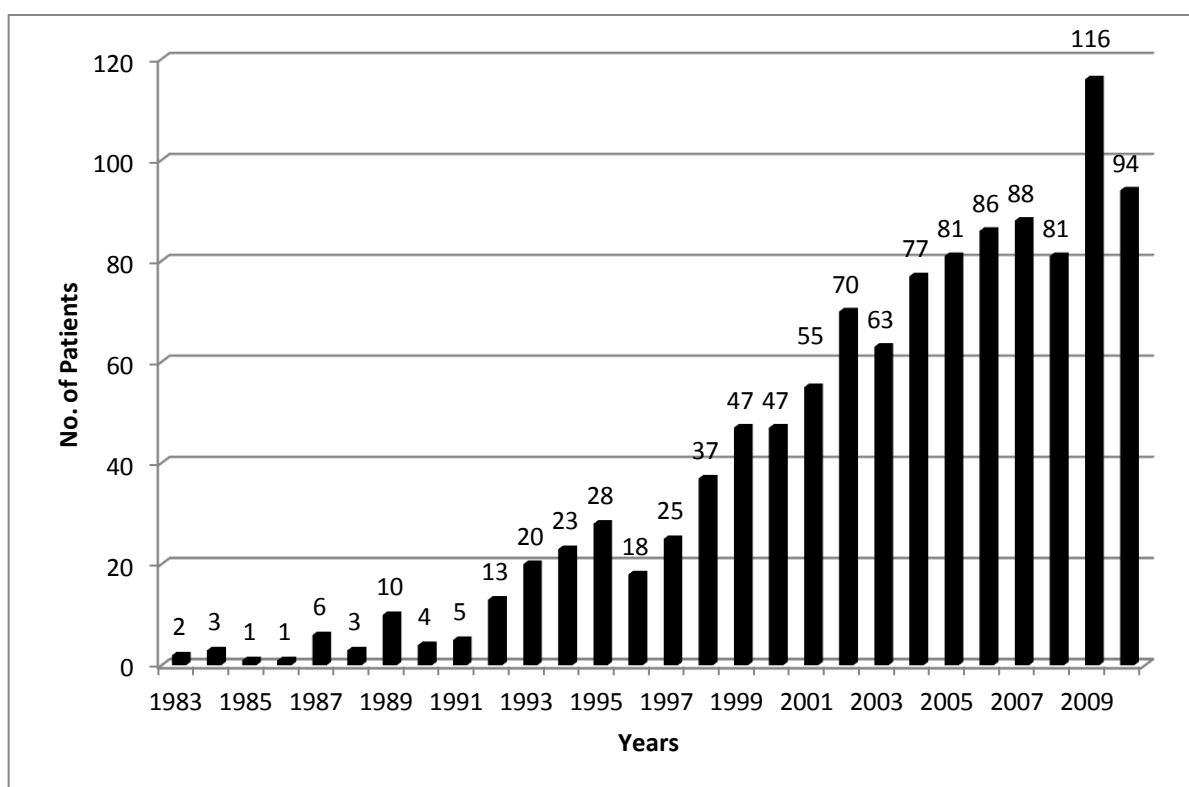
Furthermore, this study attempted to calculate the incidence rates from the year 1986 and onwards as the population censuses for Oman were available for these years. The incidence rate was calculated to describe the general incidence rates trend line. So for example, the incidence rates calculated for the years 1986, 2003, 2010, 2013 and 2015 was respectively 2.29/100,000 (22.9 pmp), 7.7/100,000 (76.8 pmp), 7.5/100,000 (75 pmp), 4.36/100,000 (43.6 pmp), 5.5/100,000 (55.3 pmp) treated kidney failure patients per total population (Table 5-7). The incidence rate calculated for the same years across Omani population only were respectively 2.8/100,000 (28.9 pmp), 10.1/100,000 (101 pmp), 10.6/100,000 (106.3 pmp), 7.7/100,000 (77.3 pmp), 9.8/100,000 (98.1 pmp) treated kidney failure patients per Omani population (Table 5-7). The Oman's RRT register reported a grand total of 3,504 new kidney failure patient since 1983-2010 (28 years), which gives mean incidence rate of 125 treated kidney failure patients per year per total population of Oman.

Table 5-7 Incidence rate for treated kidney failure patients across certain years

Year	I	Total Pop.	IR of Total Pop.	Omani pop.	IR of Omani Pop.
2003	180	2,341,000	7.7/100,000	1,782,000	10.1/100,000
2013	168	3,855,000	4.36/100,000	2,172,000	7.7/100,000
2015	230	4,159,000	5.5/100,000	2,345,000	9.8/100,000

I, Incidence; IR, incidence rate; pop., population

Since diabetes and hypertension are the major causes of kidney failure incidence across the literature, the statistics of the incidence of diabetic nephropathy (DN) were also included in the Oman's RRT register. The statistics available for DN incidence were for years 1983-2010. The DN incidence was two patients only in 1983, and increased to 94 patients in 2010 per annum per Oman. The incidence of DN from 1983 to 2010 is displayed in Figure 5-9. There were no data on the incidence of hypertensive nephropathy in the Oman's RRT register and also in the USRDS annual reports.

**Figure 5-9 The incidence of DN in Oman between 1983-2010**

- **Incidence of dialysis treatment in the four RDCs of the northern region of Oman (2014-2015)**

In 2014, RDC1 had 24 new cases of kidney failure undertake kidney dialysis; RDC2 also had 24 new kidney failure cases; RDC3 had 14 new kidney failure cases, and RDC4 had 34 new kidney failure cases. If subdivisions of the northern region of Oman were reported, the subdivision 1 incidence of kidney failure was 48 new kidney failure cases; and subdivision 2 similarly had 48 new kidney failure cases in 2014. As a whole for the northern region of Oman, the incidence was 96 new kidney failure cases. According to these statistics, the incidence rate was 17.7/100,000 in subdivision 1 in 2014; it was 10.8/100,000 in subdivision 2 in 2014; and 13.4/100,000 in the entire northern region of Oman in 2014.

5.3.3 Death profile for RRT patients (1983-2015)

- **Death profile for RRT patients in Oman (1983-2013)**

The number of deaths for RRT patients was recorded for the years 1983-2013. The reported number of deaths in 1983 was four kidney failure patients. In 2013 it was 77. Also, there were 47 deaths recorded on the Oman's RRT register from 1st January 2014 until 4th November 2014. The highest numbers of deaths among the RRT population were recorded for the year 2009 with 114 deaths. The overall recorded deaths for all years are displayed in Figure 5-10. The mean of the death rate per year, calculated for all years was 58 deaths per year. The death rate (i.e. mortality rate) for selected years were 0.004% for 2010 and 0.002% for 2013 (the denominator used is the mid-year estimate for the general population of Oman). The case-fatality rates for the same selected years were 5.9% in 2010 and 3.7% in 2013.

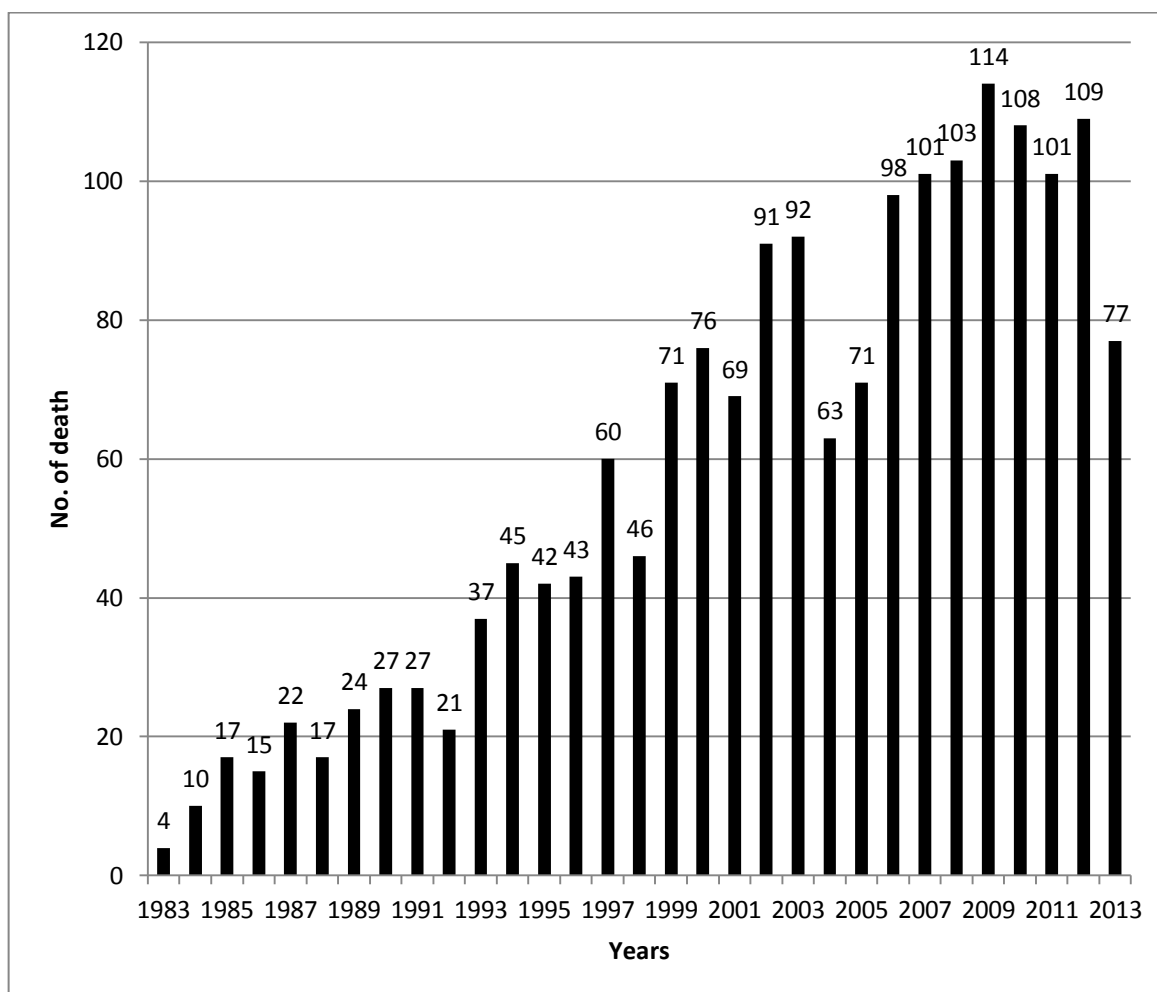


Figure 5-10 The number of deaths among RRT in the years 1983-2013

○ **Causes of death in RRT population (1983-2015)**

The causes of death for the three treatment modalities- haemodialysis, peritoneal dialysis, and kidney transplantation -were recorded in the Oman's RRT register at the central RDC for the years 1983-2010. There were seven causes of death identified as follows: cardiac causes, cerebrovascular accidents (CVA), haemorrhage, hepatic causes, infection, malignancy, and other causes where other causes were either not listed, or unknown causes secondary to not knowing the cause of death when death had occurred, as most of these cases died at their homes. The causes of RRT population death were followed from 1983 to 2010 in three time blocks which were 1983-1990 (Figure 5-11), 1991-2000 (Figure 5-12), and 2001-2010 (Figure 5-13).

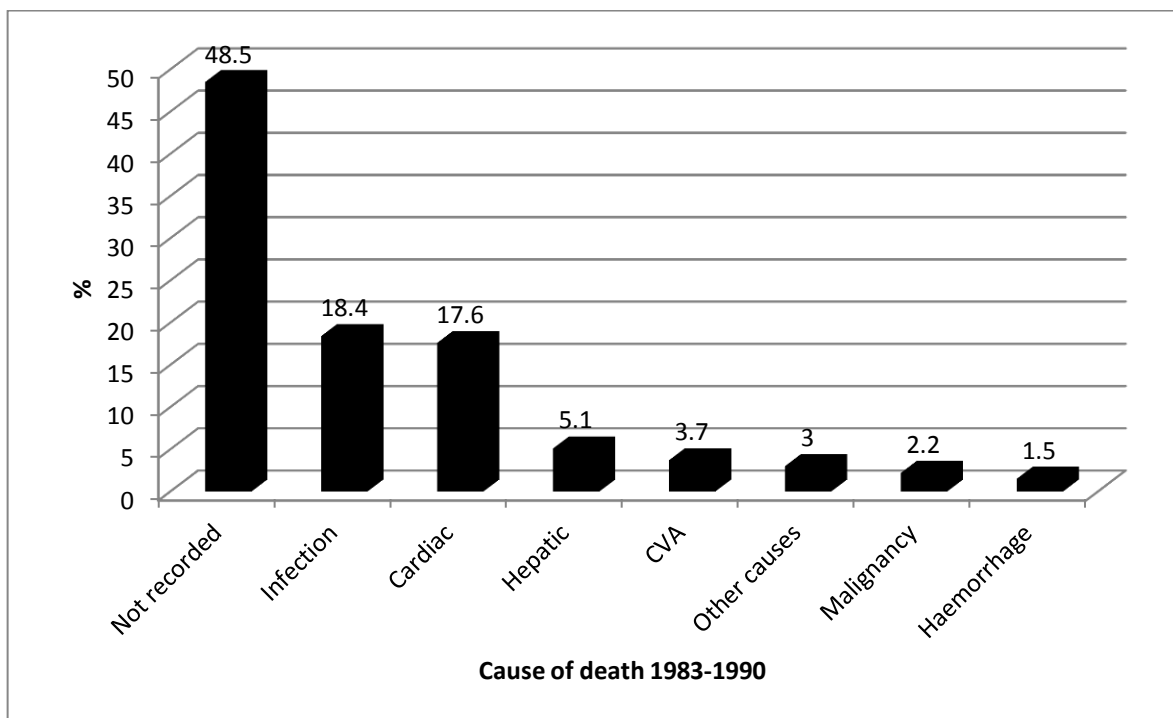


Figure 5-11 Causes of RRT population death (1983-1990)

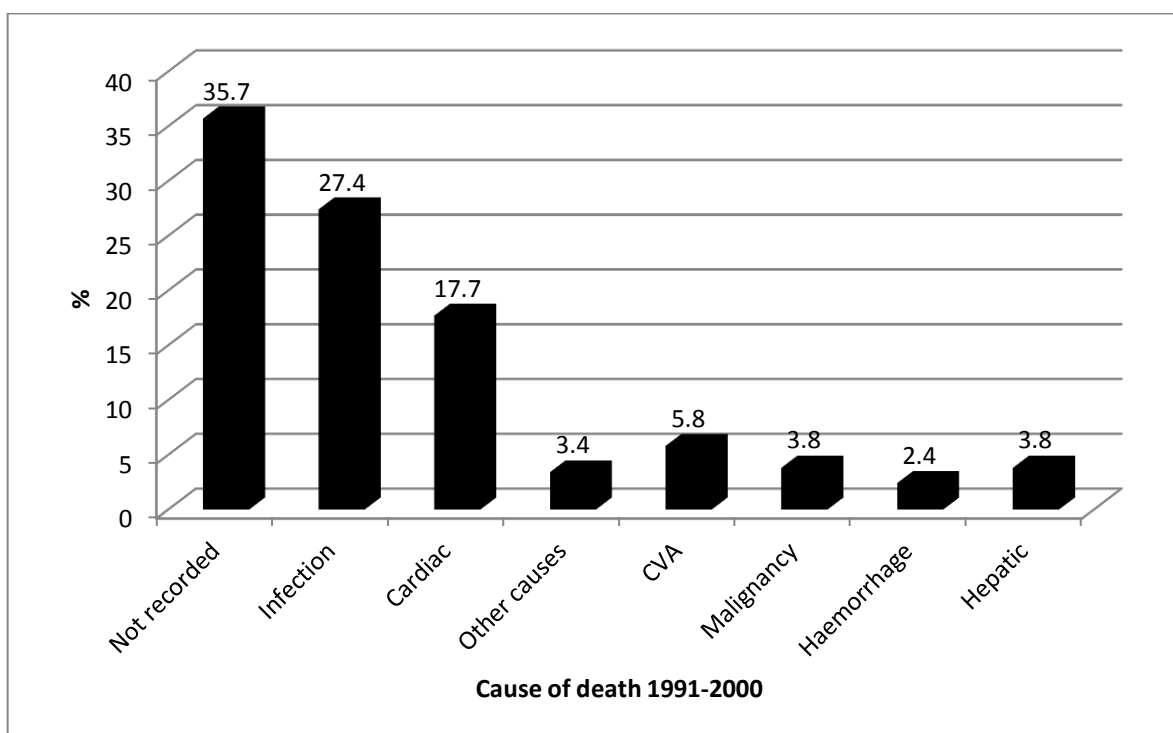


Figure 5-12 Causes of RRT population death (1991-2000)

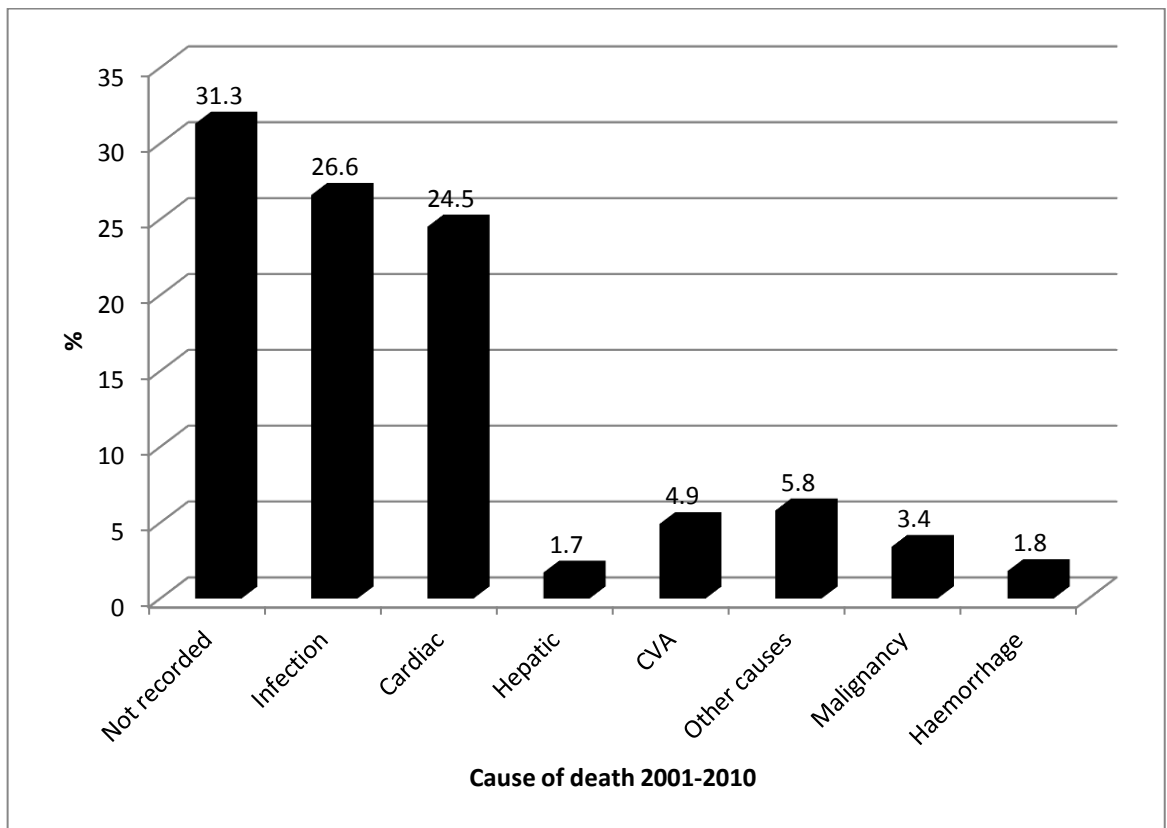


Figure 5-13 Causes of RRT population death (2001-2010)

The overall results for the causes of death statistics over the years 1983-2010 are displayed in Table 5-8. Finally, the death causes for years 2011-2015 was reported precisely in total as 449 death cause and the top three causes were unknown ($n = 148 = 33\%$), cardiovascular diseases ($n = 108 = 24\%$), and infection ($n = 107 = 23.8\%$).

Table 5-8 Causes of RRT population death across genders

Period	Cause of Death	HD Patients <i>n</i>			RT Patients <i>N</i>			PD Patients <i>n</i>			All Patients <i>n</i>		
		M	F	T	M	F	T	M	F	T	M	F	T
1983 - 1990	Not record*	28	29	57	2	6	8	0	1	1	30	36	66
	Infection	6	3	9	7	9	16	0	0	0	13	12	25
	Cardiac	10	8	18	2	3	5	0	1	1	12	12	24
	Hepatic	0	0	0	4	3	7	0	0	0	4	3	7
	CVA*	2	0	2	2	1	3	0	0	0	4	1	5
	Other	2	1	3	0	1	1	0	0	0	2	2	4
	Other cause	0	0	0	2	1	3	0	0	0	2	1	3
	Malignancy Haemorrhage*	0 48	1 42	1 90	1 20	0 24	1 44	0 0	0 2	0 2	1 68	1 68	2 136
Total													
1991 - 2000	Not record*	64	83	147	11	8	19	1	0	1	76	91	167
	Infection	29	30	59	37	30	67	1	1	2	67	61	128
	Cardiac	47	24	71	9	3	12	0	0	0	56	27	83
	Hepatic	4	2	6	5	7	12	0	0	0	9	9	18
	CVA*	16	6	22	2	3	5	0	0	0	18	9	27
	Other	7	7	14	2	0	2	0	0	0	9	7	16
	Other cause	4	7	11	5	2	7	0	0	0	9	9	18
	Malignancy Haemorrhage*	4 17	3 16	7 337	3 74	0 53	3 127	0 2	1 2	1 4	7 25	4 217	11 468
Total	5	2								1			
2001 - 2010	Not record*	13	12	258	8	12	20	4	2	6	14	136	284
	Infection	6	2	202	14	14	28	5	6	11	8	110	241
	Cardiac	11	90	204	11	5	16	0	2	2	13	109	222
	Hepatic	2	10	9	5	1	6	0	0	0	1	4	15
	CVA*	10	2	40	2	1	3	0	1	1	11	22	44
	Other	2	3	51	0	2	2	0	0	0	3	29	53
	Other cause	6	20	23	4	4	8	0	0	0	11	12	31
	Malignancy Haemorrhage*	20 24	27 8	15 802	0 44	0 39	0 83	0 9	1 12	1 21	22 24	6 428	16 906
Total	15 10 42 5	5 37 7								19 10 47 8			
Total	648	581	1,229	138	116	254	11	16	27	79	713	1,510	

M, males; F, females; T, total; Not record, not recorded; CVA, cerebrovascular accident; haemorrhage

5.3.4 Cost of dialysis treatment in Oman

The total dialysis sessions increased from 45,113 dialysis treatments in 1998 to 191,638 dialysis treatments in 2015 across the whole of Oman, as reported by Oman's MOH (Figure 5-14). So from these data, the cost of the dialysis sessions increased dramatically from 2,246,627 OMR (~ 4.5 million GBP) in 1998 to 9,543,572 OMR (~20 million GBP) in 2015 which is a 325% increase. The cost for all years is displayed in Figure 5-14.

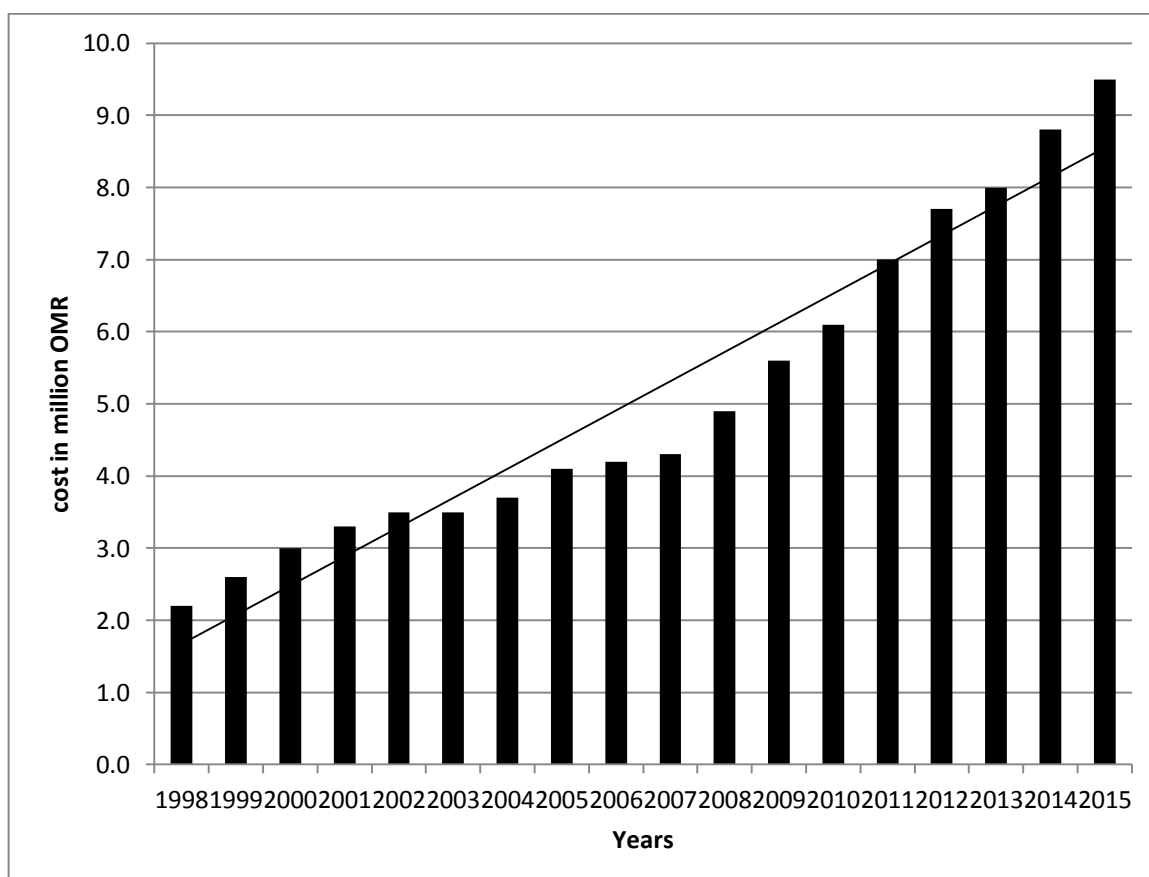


Figure 5-14 The cost of dialysis sessions per annum for Oman (1998-2015)

Also, the data collected showed the cost of peritoneal dialysis across Oman as per a letter from Oman's MOH (see Appendix C on p.252). the cost was 25,000 OMR (~50,000 GBP) per patient per year. The peritoneal dialysis patients' number was 111 patients in August 2014. The MOH expected the annual increase of PD patients to be 100 new patients per year, and therefore requested a budget of two million OMR (~ 4 million GBP) to cover the peritoneal dialysis treatment only for the year 2015. The peritoneal dialysis types used in Oman are APD and CAPD only (see Abbreviations' list, p.16).

5.4 Kidney transplantation in Oman (1980-2013)

There were no kidney transplantation centres in Oman from 1980-1988 (Mohsin and et al, 2007), so, Oxford kidney transplantation centre in the UK was the primary referral centre for live related transplantation for the kidney failure patients from Oman (Woods and Prabhakar, 1985). All Non-Related Living Donor (NRLD) kidney transplant patients were going on their own to some Asian countries like India. In other words, the kidney transplant service started for Omani citizens in 1980, but Oman had no centres providing kidney transplant services at that time, so the government was sending the patients abroad for surgery. Twenty patients underwent kidney transplantation in the period March 1983 to July 1985, of which eighteen patients survived while two died because of graft failure in NRLD transplant recipients (Woods and Prabhakar, 1985). Fifty six patients received a living donor transplantation within the MOH-Oxford Programme during the period 1983-1988.

The Oman transplantation program was initiated in 1988 and transplants were performed at both the Royal Hospital and the Sultan Qaboos University Hospital (SQUH), the two biggest referral hospitals in Oman (Mohsin, 2016). The first kidney transplantations were performed within the same year. Transplantations were performed by Pr. Abdullah Daar, Dr. Qassim Al Busaidy, Dr. Feidhlim Woods and later by Dr. Nabil Mohsin (Al-Sayyari, 2008). Pr. Daar was a pioneer in kidney transplantation in the Middle East countries (Al-Marhuby, 1998; Mohsin et al., 2007; Al-Sayyari, 2008). The first paediatric living related transplant was conducted in 1992 and the first paediatric deceased donor transplant in 1994 (Mohsin and Al-Qadi, 2014). Also, Pr. Mohsin and Dr. Daar were successful in transplanting a functioning kidney in a 17 month old recipient boy from a 33 week preterm donor with brain death in 1994. Therefore they were the holders of the World Record for the youngest donor in kidney transplantation (Daar and Moshin, 2016). Dr. Mohsin introduced peritoneal dialysis in 1993, introduced tunnelled catheters in 1993, established a paediatric nephrology services at the Royal Hospital in 1994, and introduced online hemodiafiltration (HDF) at the Royal Hospital in 2009 which was a new advanced service added to the kidney replacement therapy services in Oman (Al-Riyami, 2009).

The total kidney transplants by 1992 reached 325 where 115 were living related donors; 200 living unrelated donors; and ten cadaveric donors (Abomelha, 1996). According to Al-Marhuby (1998), the total kidney transplanted patients followed up were 174 patients in

1998. Mohsin and et al. (2007) stated in their study that from 1980 to the end of 2005, 198 kidney transplantations were performed for Omani patients from a living-related donor. In summary, the overall number of Oman kidney transplantation patients that was possible to gather, was 56 in 1988 (Woods and Prabhakar, 1985), 325 in 1992 (Abomelha, 1996), and 174 in 1998 (Al-Marhuby, 1998). The Royal Hospital webpage reported more than 800 patients who had a functional kidney transplant and were on regular screening and follow up of the hospital (The Royal Hospital webpage, 2014). The Oman's RRT register reported 955 kidney transplanted patients on 4th November 2014. However according to Mohsin and Al-Qadhi (2014), there were total of 1656 kidney transplants were completed for Omanis from 1983-2013 with ratio of 1.3 male vs. 1 female and having 690 functional kidney transplants by 2013.

Legislation for organ transplantation was approved in 1993 in Oman. The major legislation were legislation of living related donor transplants, brain death is a legal death, deceased donor transplants must be consented by next of kin, emotionally related donors must have ministerial exemption, and prohibition of commercial transaction in organ transplantation (Mohsin and Al-Qadhi, 2014). Major achievements in kidney transplantation took place in the year 2005. In this year, two vital units were established which are the transplant co-ordination unit and the kidney donor clinic. These two units helped in increasing the average of 6.5 transplants per annum to 12 by the end of 2005 and 23 by the end of 2009 (see Figure 5-15).

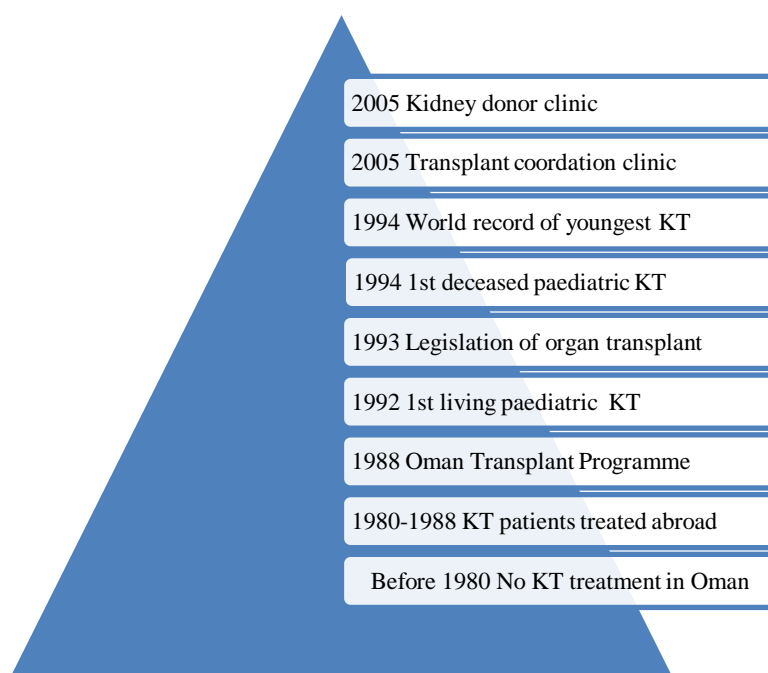


Figure 5-15 Major milestones of kidney transplantation (KT) developments in Oman

5.5 Publications on Oman's RRT population

Among the databases searched, there were 44 articles which focused on or mentioned Oman's RRT population. However, the epidemiology of kidney failure was the focus of two studies (4.5%) only (Woods and Prabhakar, 1985; Al-Marhuby, 1998 – see appendix F, p. 269); which are both older studies. There were five (11.4%) other studies which mentioned epidemiology of kidney diseases in Oman briefly (Al-Dhahry et al., 1993; Al-Dhahry et al., 1994; Abboud, 2006; Alashek et al., 2012; Hassanein et al., 2012). Kidney transplantation was the most popular researched topic for RRT population of Oman, as more than one third of the included studies ($n = 16$ studies = 36.4%) were handling this topic. The remaining articles ($n = 21 = 47.7%$) were either exploring the risk factors of CKD or discussing general topics related to RRT population in Oman (see Appendix F on p. 269). The most popular research design used were cross sectional ($n = 14 = 31.8%$), followed by observational cohorts ($n = 8 = 18.1%$), and case reports ($n = 8 = 18.1%$).

6 Discussion of study one

6.1 The main developments of Oman's RRT (1980-2015)

The first nephrology services in Oman were developed in 1980; this was an incredible achievement accredited to the pioneers of renal care in Oman. Oman at that time was only ten years old after a renaissance, and there were a lot of essential infrastructure projects being undertaken across Oman that needed budgets and attention from the top leadership. It is understood that the national health care system at that time was just in its infancy; however, nephrology care found a place to emerge within this growing health system due to its importance and urgency.

On the other hand, it can be argued that the effort was late and insufficient as the patients of chronic kidney failure had suffered low quality of life as a result of RRT not being available in Oman until 1983. Omani females had a higher occurrence of kidney failure compared to males in the early 80s, which was potentially because females experienced lower health standards compared to males, especially as most married Omani ladies (at that time) were classed as multiparity (i.e. multiple pregnancies and births) and this can lead to poor nutritional status and thereafter poor general health (Woods and Prabhakar, 1985). Multiparity could be one obvious factor for reducing the health standards of Omani females but other factors could contribute also such as diarrhoeal and respiratory diseases, maternal and perinatal conditions, and lower socio-economic status (World Health Organization – WHO, 2017). Also, the patients living in areas outside the capital continued to not have any RDC serving them until 1991. After that, 18 RDCs were created by 2012 and this number remained constant until the end of 2015 despite the increasing incidence and prevalence of kidney failure in Oman. This might imply the insufficiency of the current number of RDCs.

Oman's geographical areas are well connected via good asphalt roads and good national bus services, so the MOH can make use of these facilitators to satisfy patients' needs for convenient transportation by giving these patients access to the national bus services via offering them free bus-passes. However this latter suggestion is possible in the capital only as the bus service is mostly centred in the capital as explained earlier in chapter two (see Technological Status, p. 69). Also there is a need to provide one of the kidney failure relatives with an evidence to prove that s/he is a relative of the kidney failure patient, and

consequently allow her/him to leave their work place to escort the kidney failure patient for their dialysis sessions regularly without problems. This option may be more useful for patients who cannot use the national bus networks, especially patient from remote regions to the capital. It could be a good idea for each RDC to consider having its own transportation system, as these patients are chronic cases and most of the time have a fixed dialysis schedule, so the RDC may release a bus at each dialysis round to collect the patients prior to the start of the dialysis round in their RDCs and then take the patients back to their homes when they completed their dialysis. However, the best solution for transportation is to increase the number of satellite RDCs to be within walking distance of patients' homes. This latter will increase the cost for the health system, as to run any RDC properly will require costly resources like staffing and machines. Furthermore, these patients may want to find life insurance as they use the traffic more frequently than normal people and therefore they are at higher risks of road traffic accidents, equally there are some cases already reported who have died on roads during their journeys to and from RDCs.

Furthermore, the most densely populated governorates of Oman were respectively, the capital (310.4 person/km²), the northern region (81.3 person /km²), the peninsula (22.1 person /km²), the eastern region (14 person /km²), and the interior region (12.6 population/km² - Table 3-1). It was described that the top number or percentage (30% - Figure 5-6) of RRT patients since 1983 and until 4th November 2014 was reported in the capital and the northern region (25%), interior region (14%) and eastern region (12.2%), while the least number or percentage (less than 1.5% from each region) of RRT patients were coming respectively from peninsula, west end and middle regions. Accordingly, the MOH established three RDC in the capital, four in the northern region and four in the eastern region, two in the peninsula, two in interior region, and one in each of the following: southern region, western region, the west end region and none in the middle region (Table 7-1) in an attempt to well serve all patients. It is understandable that the MOH established, for example, two RDCs for the peninsula region which have few patients (less than 15 dialysis patients) but also have a complex topographical area.

From chapter two, it is known that Oman leadership prioritize the health needs of Omani populations as an important and urgent need. Therefore, time now has come to evaluate these needs especially that more than 35 years has passed now since this care has started in Oman. The Public Health Action Support Team (PHAST; registered in England and

Wales, 2011) suggest that measures of supply and demand are key indicators for “local performance management” and “capacity planning of health care providers”. The Public Health Action Support Team suggests that measuring of supply can include measuring of staffing e.g. nephrologists or renal nurses, dialysis stations available for patients, equipment e.g. haemodialysis machines, budget e.g. funds available and income, and ability to manage waiting times as increasing waiting time may suggest shortage of supply and increase in demand. So this thesis results encourages Oman’s MOH to measure the supply and demand of renal care (if not yet done until this moment) so this will help in making the necessary renal care available and will indicate the number of renal care services the population needs. The present data show that the catchment area of one RDC is 0.22 million Omani population. The data from renal registries showed variations in ratio of the catchment population to the renal dialysis centres. Broadly speaking, for example, in the UK which had around 65 million populations in total by end of 2015, there were 71 renal dialysis centres which give a ratio of 0.92 million populations to one RDC. In KSA which had around 31.5 million population in total by end of 2015 (213 RDCs) the ratio is 0.15 million to one RDC. However to have more specific comparison, the dialysis stations in KSA were 6560 in 2015 compared to 213 dialysis station in Oman, the ratio respectively were 2.4 haemodialysis patients to one dialysis station in KSA and 6.6 haemodialysis patients to one dialysis station in Oman. The ASN Dialysis Curriculum (Randolph, 2016) recommends that an “18 station facility can dialyze a maximum of 108 patients utilizing all stations 6 days per week, three patients shifts per day”. In RDC2, for example, there were 240 dialysis sessions performed in the 6 days of the week utilising 13 dialysis stations which imply that the supply is less than demands in this RDC.

6.2 Main statistics about Oman’s RRT population

The overall trend described from this study showed an increase in the prevalence of treated kidney failure across Oman. Also the prevalence of dialysis cohort increased steadily since 2007 to 2015 with dramatic increase between 2011 and 2015 - Table 5-2). In comparing prevalence of the dialysis cohort reported by this study (332 pmp/2013) and reported by USRDS (358.5/2013), it is showed that Oman’s prevalence is less than KSA (499.4 pmp/2012 – no figure for 2013), UK (432.2 pmp/2013), but higher than the Bahrain (250.2/2011 – no figure reported for 2013), and Qatar (316.7/2013- Poland and Italy were not reported). The prevalence figure of this study agrees with the prevalence figure of the

USRDS which may imply that the figures reported for Oman's dialysis cohort are more genuine to what was encountered by the author while gathering field data.

There were some dips described in the prevalence of treated kidney failure in Oman in years 2003, 2005, and 2006. The reasons behind these dips were not clear for the year 2003, but for the year 2005, it could be due to the closure of one of the RDCs. In 2006, it could be due to the Gonu cyclone that hit Oman in 2006. The cyclone destroyed some of the roads especially roads in Muscat (the capital), so this situation could have stopped people from going for dialysis for a while and therefore these patients dropped from the statistics of year 2006. Also, it could be that some kidney failure patients died during that weather disaster in 2006. However the dips occurred did not affect the increasing trend of kidney failure prevalence in Oman, which is evidenced by the the graph bars representing the prevalence for all years across Oman (Figure 5-3). Also comparable year points were allocated for years 2003 and 2013, and 2015 and showed an overall increase trend for dialysis treated patients overall Oman across the total population and across the Omani population (Table 5-2).

This research study attempted to compare the prevalence rates in between total population and Omani population to explore if the difference between the two rates is wide or narrow. This attempt was made because there are no distinct figures for prevalence of dialysis treated patients of Omanis to non-Omanis. Is it essential to do this distinctions, perhaps the answer is no, but because the author believes that the prevalence rates of total population is inflated and it does not represent the actual figures of prevalence of the country so this attempt was made. However, the comparison presented here showed a widening gap in the prevalence figures between total population and Omani population. Though the prevalence increased at both sides of comparison but the prevalence in the Omani population is approximately double that in the total population. The author believes that though the numerators used to calculate the prevalence for total population and for Omani population are the same (i.e. combined of both), the prevalence figures for Omani is closer to the real figures when the non-Omani population is excluded from the denominator (it is preferable to exclude non-Omanis because non-Omani population is high in census but their dialysis treatment figures is very small at present). The rationale behind this assumption is that the difficulty in capturing the dialysis treated cases occurring in non-Omani population because usually these patients go back to their home country for treatment, treated in the private sector sometimes and if they cannot afford treatment they may return to their own

country at some point in time. This means that the number of expatriate on dialysis, at least in the north of Oman, is small and this is evidenced by the field data collection of study two, where only three patients (0.8%) were excluded from the study because they were expatriate. Based on this assumption, the prevalence reported for total population is inflated (due to the high proportion of non-Omanis who are few of them on dialysis) and should be adjusted by distinct statistics for kidney failure cases occurring among expatriate and among Omanis and thereafter the combination of both can be made on clear judgment of the real figures or at least close to real figures.

The prevalence rate among dialysis sub-population for the Omani population was 61.4/100,000 (614 pmp/2015), but for the total population the prevalence was 34.6/100,000 (346 pmp/2015). However, the reported prevalence rate for Oman in the USRDS (2015) was 656 pmp/2013 per total population for Oman's treated kidney failure population, and 358.5 pmp/2013 for Oman's dialysis sub-population. As a result this study reported prevalence for dialysis sub-population per total population agree with what reported by the USRDS (2015). Also, this study and the USRDS (2015) agree on that Oman is among the countries that have lower rates of RRT and dialysis treatment prevalence (the data interpretation in this thesis is the responsibility of the author and no responsibility should be made on USRDS or any other registries or any other data source).

Also, when the overall trend of prevalence was described across the four RDCs of the north of Oman, there was a drop in the overall prevalence; this was more noticeable in the last three months of the year 2014. This drop happened secondary to the drop in RDC4 prevalence in 2014. The author believes that this is a typing error on the MOH reports as the on field reported RDC4 prevalence for the year 2014 was 97 and not 41 as found by the author at the time of data collection (Table 5-5). Also, it is noticeable that there were drops in the prevalence of dialysis patients in RDC4 in months January and February 2014, and again in October – December, 2014 with no clear reason.

This study shows that the highest prevalence rate per 100,000 Omani population in 2015 was in the west end region, the capital and the southern region (Table 5-3). So it can be argued that the number of dialysis centres in these governorates are not sufficient at present and has to be increased in predictions for the dramatic increase in the prevalence of kidney failure patients in these governorates. In the capital, two of the three dialysis centres are close to each other in distance and the third one is around 100 km away from the first two.

So a governorate with 3900 km² size perhaps needs more dialysis centres to serve its kidney failure population, especially with increasing load of dialysis secondary to the increasing in prevalence. However, at the time of writing this chapter, there was one additional RDC established to serve the dialysis cohort in the capital which increased the number of RDCs to be four in the capital itself. Also, another RDC was established in the northern region of Oman, and so there are five RDCs in the north which again support what this study has found. In general, this indicates the good planning by the Oman's MOH and indicates that Oman's MOH noticed the increasing prevalence of treated kidney failure across Oman and it is responding accordingly. However, in the west end region and the southern region, there was still the same number of RDCs which was one RDC per governorate. Therefore there is an urgent need to increase the number of RDCs across these governorates and across the entire country as well.

Two factors need be considered when planning for RDCs' capacity; these are the density of the population in the catchment area around the RDC in relation to the current prevalence of kidney failure and the future prediction of kidney failure incidence. The distance between the RDC and patient homes and the topographical feature of the area has also to be considered. The patients should have an easy transfer to and from the RDC without exacerbating complications and should avoid unnecessary road traffic. Transportation is identified as one of the factors that can lead to non-compliance with the in-centre dialysis (Latham, 1998; Chan et al., 2014). Therefore Oman's MOH has to facilitate transportation for the dialysis sub-population to achieve the best outcomes of dialysis compliance.

The overall incidence rates were fluctuating (Table 5-7) as also demonstrated by cumulative incidence of years 2010 and which were respectively 0.007% of RRT event in 2010 and 0.004% of RRT event in 2013 across the total population. This study reports incidence rates for Oman's RRT population, for example, 22.9 pmp/1986, 76.8 pmp/2003, 75 pmp/2010, 43.6 pmp/2013, and 55.3 pmp/2015, and a mean incidence rate of 125 treated kidney failure cases per year. Also, it was described that the recorded incidence peaked in the year 2009 with 247 treated kidney failure patients. It could be secondary to the peak in diabetic nephropathy incidence registered in the same year. The mean incidence figure found across the years up to 2015 was 135.8 treated kidney failure patients per annum. The overall described trend for incidence was an increase if described across the actual incidence figures (Figure 5-8); however, the increase was not linear because

there was fluctuation in the incidence of some years (Figure 5-8). In contrast, the USRDS reported Oman's incidence rates respectively as 102.1 pmp/2008, 103 pmp/2009, 106 pmp/2010, 108 pmp/2011, 110 pmp/2012, 120 pmp/2013 (United States Renal Data System – USRDS, 2015). Though, the trend line of USRDS about Oman's RRT incidence rates show consistent increasing trend, this study incidence rates show an increase if described across the actual incidence figures (Figure 5-8); however, the increase was not linear because there was fluctuation in the incidence of some years (Figure 5-8), which is demonstrated by the cumulative incidence rates that were possible to calculate for some selected years (i.e. 0.004% in 2010 and 0.002% in 2013 RRT event). However, it is most likely that the incidence is under reported secondary to late presentation of these patients for medical care or no capture of these cases at the first instance due to pre-mature death or being treated in out of the country.

This study reported mean incidence rate of 125 treated kidney failure per year per total population of Oman. On the other hand, the USRDS annual report (2015) reported incidence rate of 120 pmp in 2013 (if the total population in 2013 was 3.855 million, then the actual figure of incidence was 462.6 (120X3.855) per Oman's population and not 168 new cases (i.e. 43.6 pmp) per Oman's population as reported in Figure 5-8. As a result, the two incidences are not exactly in agreement with each other, however the incidences reported by this study is believed to be more precise as they were gathered through on the spot field work and were gathered from an original source which is Oman's RRT register.

Similarly, this study results are compared to data published to any of the GCC countries' data as available. Oman is part of the GCC countries which are all neighbouring countries whose population shares many characteristics with that of Oman, such as religion, language, borders, weather and more. Furthermore it is seen fruitful to compare Oman's statistic with Italy or Poland as Oman's land area is almost the same to that of Italy or Poland, though their population is far larger (~38 million in Poland vs. ~65 million in Italy/2013) than Oman's population (~four million). Accordingly, Oman's incidence rate (43.6pmp/2013) was the lowest when compared to KSA (127.3pmp/2013), Bahrain (207.5/2011 – no figure for 2013), Qatar (100 pmp/2013), Italy (162 pmp/2010 – this was the only reported incidence for Italy across years), Poland (126.2 pmp/2013), and UK (112.5 pmp/2013). Oman's incidence rate is even lower than Bangladesh (45pmp/2013) which is the lowest reported incidence across the participant countries of the USRDS (2013). However, the actual figures of incidence could be higher if calculated across

Omani population only and not across the total population of Oman (Table 5-7). Also what all figures displaying here are only for the treated population and definitely there are some proportion of this population who are missed because of not being under treatment or having the disease and not yet detected.

The incidence of Oman's treated kidney failure due to diabetes (45%/2010, result of this study, and 46%/2013 reported by USRDS, 2015) was the highest if compared with KSA (38.8%), Kuwait (40%), Qatar (32%), UK (22%), and Poland (21%). The both figures regarding this aspect from this study and USRDS agree with each other. Oman has no data on hypertensive nephropathy to compare for example with KSA which has 39% of their treated kidney failure patients had hypertension.

Similarly, the incidence and prevalence when described across the four RDCs and across the two subdivisions of the north region, it again showed rising figures. In particular, that the RDCs of subdivision 1 had a higher incidence compared to subdivision 2. The incidence of dialysis treatment in the four RDCs was not possible to calculate for the year 2015 due to some shortage in the data provided. Furthermore, this study provides a closer observation to these rising figures, it is noticed that despite the lower population of subdivision 1 compared to subdivision 2, the incidence and prevalence of subdivision 1 were higher. Also the comparison between the regions showed higher figures in the capital and west end and lower figures in the west and the north of Oman. Accordingly this data provide clues on treated kidney failure population mapping of Oman which could be secondary to many reasons represented by BEINGE model, for example, cross-population variations in age or gender, and variations in socioeconomic status of the population. This data on kidney failure occurrence across Oman signpost toward further studies to emphasise these data and explore the aetiology and risk factors led to the variations in occurrence across the regions of Oman.

This study found that treated kidney failure male figure (54.5%) was higher compared to females (45.6%) which is compatible with KSA data (55% males to 45% females) and with all registries described in chapter one of this thesis (see p.36). USRDS (2015) had no data on genders ratio of Qatar and Poland, and for the UK it was 61.8% treated males to 38.2% treated females. This data imply that there is a need to investigate the reasons behind having more kidney failure prevalence among males than females. Though the

difference was not high in Oman's context and it could be as a result of having more male population compared to females in the general population census. Higher prevalence among males of Oman could be because they are at high risk of getting the kidney failure or it could be because they have long duration of disease and so they live longer and add up to the prevalence (cumulative), or it could be because the incidence of kidney failure is higher in men than woman. Also possible explanation could be that kidney failure among men is detected earlier secondary to their early attendance for the medical check-up compared to women in Oman and therefore men proportion of prevalence appears higher because they were being diagnosed earlier than women who are diagnosed late. However studying gender differences in a disease context can provide valuable understanding on differential susceptibility (Altevogt et al., 2011). Comparing different variables such as the role of genes or effect of identical treatments in males to females can discover valuable data such as the protective factors that exist in females that could protect them against diseases or how a treatment can be modified to best treat each gender (Altevogt et al., 2011).

Understanding the relationships between incidence, prevalence and case-fatality can provide a deeper description of the epidemiology of any disease. It is well known that prevalence is the function of two main factors which are incidence and duration (i.e. Short or long term duration to death – LaMorte, 2016). In this case, the prevalence of RRT event found rising within population of Oman; incidence were fluctuating, mortality rates and case-fatality were fluctuating too. As a result, it is difficult to infer the existence of positive relationship between prevalence, incidence and case-fatality because of the fluctuation of the later. It is most likely that the duration of the disease is long and therefore the prevalence is rising as demonstrated for example by the morality rate in 2013 was 0.002% and the incidence was 0.004% (i.e. incidence figure is more than death figure). Accordingly only 0.002% died while the other remaining 0.002% of the incidence was added up to the prevalence of the next interval and causes rising of prevalence figures. The same can be applied on diabetic nephropathy incidence, prevalence and case-fatality. So if the trend of DN is described for the last five years from 2006-2010, it can be noticed that the DN increased from 38.6% in 2006 to 47% in 2009, then it dropped slightly in 2010 to be 45%. The data reported in the USRDS (2015) for Oman were similar, as the USRDS reported 46% (Oman was the top 8th country in having diabetes among the participant countries of the USRDS) of DN among the incident cases of the year 2013.

The death profile for the RRT population was maintained very well in the Oman's RRT register and helps to reveal that the most reported leading death factors among this population. The described trends show that the common three causes of death were: not recorded, infections or cardiac complications. However, the un-reported death causes were applied to a considerable number of these patients which, if reported, could change the present causes of death profile. For example for the years 2001-2010, there were 284 (31.3%) deaths with no recorded cause of death, out of 906 (100%) patients who died in these years. It was known that most of the unreported death events took place at patients' homes. However, it might be a good idea to advise the families to escort the patients immediately after death to the nearest hospital to report the cause of death before burying the body. This could improve the reporting statistics of death and causes of death. Furthermore, the data provided by literature showed that the cardiovascular factors were the most common causes of death for this population which suggests that this is most probably the cause of death for the unreported causes of death. However, this claim needs further testing in the context of Oman.

It was described that the figures of all causes of death appeared to be higher in the haemodialysis (which is the main treatment modality provided for Oman's RRT population since this treatment has started in Oman - Table 5-8) cohort compared to the kidney transplants and peritoneal dialysis cohorts (Table 5-8). The death figures appeared to be higher in males ($n = 797$) compared to females ($n = 713$) in all treatment modality cohorts except peritoneal dialysis cohort where female deaths ($n = 16 = 59.3\%$) appeared to be higher compared to males ($n = 11 = 40.7\%$ - Table 5-8). This data is well-matched with all registries data. Males' death figures were higher compared to females in all cohorts except in peritoneal dialysis cohort which suggest the need for further explorative and investigative studies to reveal the causes and risk factor behind these variations.

There was a decline in death events described since 2009 which can have an important impact on both kidney failure patients (i.e. increased survival lifespan) and resource allocation (i.e. increased survival will cause increase demands for more resources). It is useful to study what were the strategies adopted in these years of death decline, so they could be studied further, modified if necessary and included in the care plans of the long term.

According to the data from this study, the prevalence of dialysis patients overall Oman in 2013 was 58.9 dialysis patients per 100,000 Omani populations (i.e. 589.8 dialysis patient per million populations). This figure of prevalence is equal to 0.06% of the Omani population having dialysis treatment. However, the cost of dialysis treatment in 2013 was 1.36% (i.e. 8,071,484 OMR) of the MOH budget (593.7 million OMR), which drains a considerable amount of budget; it is around 6,300 thousand OMR (direct cost only) per patient per year. This cost is recurrent as these patients have a chronic condition and are undertaking a lifelong treatment (i.e. dialysis). As discussed in chapter two, the epidemiological profile in Oman is shifting to have more of an elderly population as the life expectancy is high in Oman; also the diabetes prevalence is increasing which is most likely one of the leading causes of kidney failure in Oman. These figures predict that the cost of RRT will increase across the coming years and the country should be prepared to accommodate the growth in demand for this treatment. Therefore, it is important to secure funding to continue providing adequate renal care for the Omani population.

Also, secondary to the increased demand for renal care, there will be a rise in related costs, for example increased demands on renal care staff that will need to increase in number with associated training and salary costs. This study results inform the renal care team, and especially renal nurses, to keep themselves up to date and be prepared for more load and challenges in dealing with the treated kidney failure population. The evidence from this research can be used to inform renal care leadership to undertake other cost-effective modalities, such as peritoneal dialysis, which may have better outcomes for the kidney failure population. The current proportion of peritoneal dialysis patients in Oman is small and did not help to reduce the workload and cost very much. As reported earlier in the literature review, peritoneal dialysis is a patient self-managing treatment and is also a cost-effective treatment. This should be a motivator for the Oman's MOH to undertake this type of treatment to a greater extent.

6.3 Kidney transplantation in Oman (1980-2013)

Kidney transplantation care took a long time to launch in Oman; it was only started in 1988. The number of transplantations conducted in Oman was only 23 in 2009; this is a limited success. The number of kidney transplantations has to be increased. The KSA and

Kuwait have successful programs of kidney transplantation which might inform the kidney transplantation program in Oman to adopt some changes to the existing system to make the program more successful. However, the MOH has provided all the resources for successful kidney transplantation program in Oman such as the transplant coordination unit and kidney donor clinic. The program was able to achieve the World Record for the youngest donor in kidney transplantation which imply that the program has the potential to perform the most difficult kidney transplantation surgeries. Also, the USRDS (2015) provided kidney transplantation statistics for Oman (18pmp/ 2013 kidney transplants per annum) which is comparable with KSA (18.6 pmp/2013), Kuwait (16.6 pmp/2013 kidney transplants per annum), higher than Bahrain (6.7 pmp/2012), but less than Poland (29 kidney transplants per annum), and UK (51 kidney transplants per annum). This infers that there is no apparent problem within Oman kidney transplantation program but the main problem could be the shortage in the number of donated kidneys as there is no sufficient living or deceased donors at present for Oman's kidney failure population.

The USRDS (2015) reported many developed countries receiving more of donated kidneys from deceased donors compared to living, for the developing countries reported in the USRDS (2015) like Kuwait and Qatar, it was described that there were more living donors compared to deceased, in Oman in two thirds of the kidney transplant donors it is unknown if they are deceased or living (Figure 6-1). Also the general trend of the functioning kidney transplanted prevalence across the GCC reported by USRDS (2015), showed reduction, for example Bahrain had 52.7 functioning kidney transplant pmp/2011 compared to 53.5pmp/2010; Qatar had 332.4 pmp/2013 compared to 375.5 pmp/2012; KSA had 252 pmp/2012 compared to 298.4 pmp/2010, and in Oman there were 297.4 pmp/2013 compared to 331.1 pmp/2012. Therefore, the challenge is to disseminate the organ donation culture among Oman's population, also to be transparent in telling the facts about the shortage of kidneys to the public and if possible ask the patients themselves to speak up about their difficulties and their need for organ donation. Many kidney failure patients on dialysis feel desperate for having no donors available to help them. In some instances, these patients travel abroad to seek commercial donation, which is considered by the international and national communities as unethical. This kind of transplantation plan is not supported by the MOH of Oman. Commercial kidney transplants expose the patients to higher risk of infections, organ rejections and death.

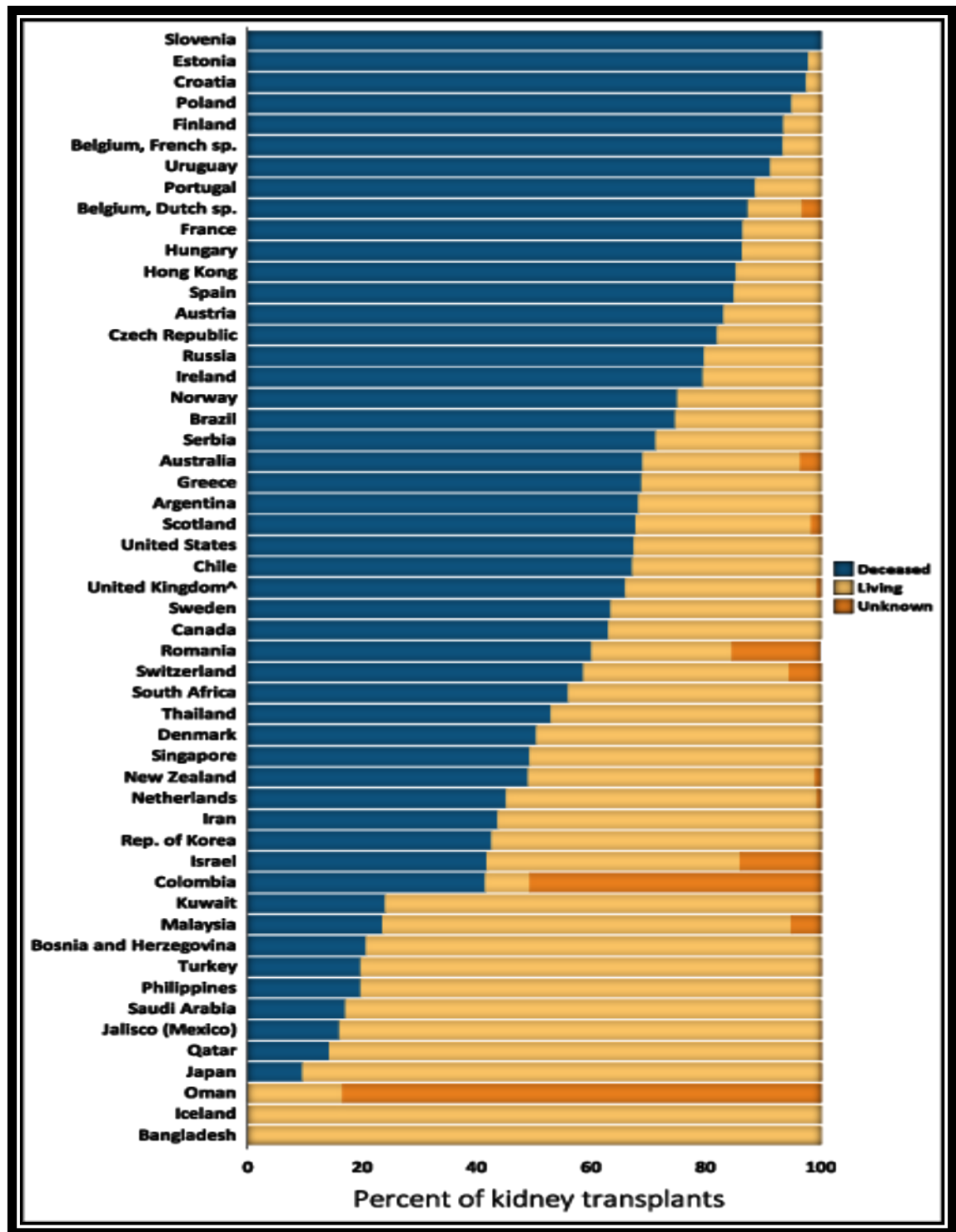


Figure 6-1 Distribution of kidney donor type across countries, 2013

© United States Renal Data System. 2015

Furthermore, the statistics of Oman's kidney transplantation is not consistent as reported earlier because only few statistics for kidney transplantation were possible to be gathered by this study. So far, there is no national study covered the epidemiology of kidney transplantation in Oman and attempted to explore the facilitators and barriers of this important program in Oman. All renal registries and societies across the board agree on kidney transplantation as the best option for kidney failure patients. Therefore, the Oman's

MOH can dedicate research manpower and resources to explore and examine this treatment in Oman and invest more if needed to increase the annual statistics of kidney transplants in Oman. Equally, the patients themselves should be educated about the best treatment option for them and allow them to have objective stance to choose what treatment of favour to them.

6.4 Publications on Oman's RRT population

In general, most of the identified 44 publications were difficult to appraise because they lack some key information on the method conducted, on the missing data, and on the limitations encountered by these studies (see Appendix F on p.269). However, this again question the reliability of the research methods used in these studies and emphasises the hypothesis of a quality knowledge shortage regarding the RRT population of Oman.

The publications on kidney transplantation were relatively acceptable in number ($n = 16 = 36.4\%$) but limited in their scopes and methodologies because many of them were case reports where their reported data and their generalizability are limited. Similarly, the studies on the epidemiology of Oman's RRT were limited in their number and methodologies. Only two studies with older dates (1985; 1998) contained some details of Oman' RRT population. Another five studies mentioned Oman's RRT partially but most of them emphasise on the fact that there were limited data and studies coming from Oman. This shortfall applies not only to kidney failure research but to the overall situation of biomedical research in Oman, which is still considered of limited benefit (Ministry of Health - MOH, 2014). There were 141 countries assessed by SC Imago Journal and Country Rank portal for the number and citations of publications during 1996-2010. The study reported that Oman had only 1,522 publications with 7,357 citations; Oman was ranked ninth among 15 countries in the Middle East and North Africa region in research activity. Also, more than one-quarter of the biomedical publications (period 2005-2009) by Omani researchers were published in journals with no Impact Factor (IF) while more than half were also published in journals with IF value of less than one (Rohra et al., 2011). Therefore, the Omani research studies were found to be of limited practicality (Rohra et al., 2011; Ministry of Health - MOH, 2014).

6.5 Conclusion

This study found that the data archived in the Oman's RRT register in the capital of Oman is worthwhile and clinically significant. So it can be argued that the data provided in this study and with a complementary data from Oman's RRT register can have the potential to form the base for an Oman Renal Registry (ORR). The goal of ORR can be something similar to that of other registries such as the UKRR's goal which is to improve the health of the kidney failure population through making the necessary changes to the renal health care system as a result of the registry data. Registry data can be useful in testing hypotheses and providing evidence of the need of research (United Kingdom Renal Registry - UKRR, 2016). Research can be of great benefit if utilised well. UKRR (2016) suggests adopting the "Translational Public Health Research" to achieve the maximal benefit from observational data and other data coming for example from international trials (Figure 6-2). On the other hand, if Oman's MOH see difficulties in launching the ORR at present, then it is suggested if the ministry extend the existing published annual data about Oman's dialysis population. For example to include distinct detailed statistics for all the three treatment modalities in Oman while distinguishing the statistics of Omanis and non-Omanis, males and females, living and deceased especially for the kidney transplantation cohort, and including the direct and non-direct cost for all modalities. Also it is worthwhile to improve the present reporting strategies by for example creating electronic renal network where all renal data can be entered and retrieved with a back-up plan in place. The entered data must be reviewed and ensure of its reliability and validity prior publishing them.

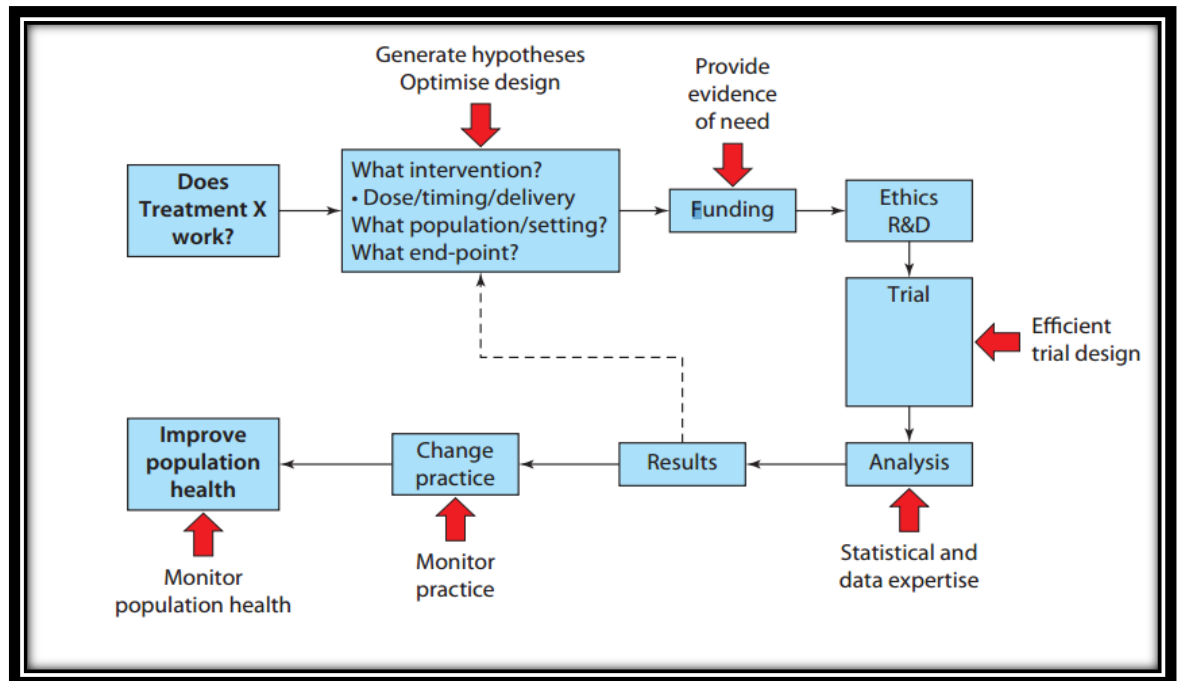


Figure 6-2 Translational Public Health Research
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The data provided by this study are paving the road for further research studies needed in this field. For example, this study shows the geographical variations in incidence and prevalence of kidney failure between governorates, which highlights the need for conducting research to explore the causes and risk factors (BEINGS) responsible for these variations, which might be population differences or variations in the age structure of the population. Also, there is a need to conduct studies to measure the present situation of supply and demand of renal care so capacity planning will be signposted especially toward the urgency of creating more satellite RDCs. Also research studies' results have to be published and accessible for the concerned parties.

Also, the study found that the popular modality available for kidney failure Omani patients is haemodialysis (despite the higher death figures reported in this cohort) and few patients had the chance to be on peritoneal dialysis treatment, for example. This study's data can be the base for further research to assess the equity of access to these modalities, and to assess whether patients are offered sufficient information and options to select from. So far organ donations culture needs to disseminate among Oman's population through perhaps strong awareness program that reach all people of the country.

The study showed some dips in the prevalence of kidney failure like in 2003 and 2005 with no clear justification. This result may be explored further to see if they were actual dips and then to consider the explanation for them, to help in understanding the theory behind the dips, and then perhaps adapting some strategies to achieve a continuous decreasing trend for kidney failure in Oman. Also, it is known that the MOH had established a national screening program in 2010 and published the protocol of it under the title of “Operational and management guidelines for the national non-communicable-disease screening program”. This screening program targets all Omanis who fulfilled the following criteria: they are 40 years old and over and never diagnosed with chronic kidney diseases or diabetes or hypertension or even with obesity or elevated cholesterol. However, it is more than five years now since this program was established and there is no decrease in prevalence but a slight decrease in incidence since 2010. It is not known whether this program has resulted in this slight reduction or not, therefore, it is important now to evaluate the impact of this program on the epidemiology figures particularly the incidence of kidney failure in Oman, and on people’s awareness of kidney failure and RRT.

Also, one significant result was the dramatic increase in the prevalence rate of kidney failure in between 2011 and 2015. This increase needs to be studied to explore if it happened secondary to the dramatic increase in the non-Omani population in these years, or secondary to the increase of diabetes incidence among Omanis, or maybe there is another theory explaining this observation.

This study recommends secure funding to be sustained, it is very important to continue providing adequate renal care for the Omani population. Oman as a high-income country has to direct all income sectors (oil and non-oil resources) of Oman to participate in supporting the health sector services and research activities to maintain high standards, because these two are the main generators for the developments of the country.

In conclusion, this study suggests that there is a great need to do further research in this field. The renal research field in Oman is starving for more data to be gained about the kidney failure and RRT population. The first step is to conduct research to uncover the characteristics of this population, to gain more understanding on what the kidney failure population in Oman looks like and if it is similar to other countries’ populations or is it unique with different characteristics. This recommended research was already conducted by the author, and it is reported in the next chapter as study two.

7 Methods of study two

7.1 Introduction

This cross-sectional study (i.e. survey research) was conducted mainly to identify and describe the kidney failure population undergoing dialysis in Oman, and their main characteristics. However, due to the high expense and limited resources and limited time, it was planned to describe a sectional representative population who live in the northern region of Oman instead of observing the entire Oman's dialysis sub-population. Further exploratory analysis using the data collected in this cross-sectional study was conducted, for example exploring how the descriptive statistics obtained differ for the different locations in the northern region of Oman. This chapter presents all the information required to understand how the cross-sectional study was conducted and how its data was analysed. The cross-sectional study main objectives were as follows:

5. To identify the demographics and characteristics of patients undergoing kidney dialysis in the northern region of Oman.
6. To identify the common primary diseases, co-morbidities and risk factors associated with the kidney dialysis population in the north, and compare it with the neighbouring countries if data is available.
7. To describe the present kidney dialysis modalities in the northern region of Oman.
8. To describe briefly the characteristics of haemodialysis, and how haemodialysis impacted the quality of life of patients in this sub-population.

7.2 Study design

The cross-sectional design was selected for this study because it was the best match for the study's research questions and objectives, as it was intended to study a sectional representative population of kidney failure patients in Oman. The cross-sectional design is used widely in studying diseases and their risk factors in a pre-defined representative population in a defined period of time (Bhopal, 2008). This design can be used to compare sub-groups within a geographically defined place based on their diseases, risk factors and other factors, because undertaking national studies can be expensive and difficult to manage (Bhopal, 2008). It can also be used to assess health needs or the burden of health

problems within societies. Cross-sectional studies can be descriptive, describing the frequency and distribution of health problems in the identified population, or they can be analytical, examining the relationships between some risk factors and health outcomes (Bhopal, 2008). This cross-sectional study is mainly descriptive.

Cross-sectional studies are used across the literature to provide a snapshot of studied phenomenon such as health or disease (Bhopal, 2008). Most cross-sectional studies collect data in a very short time (a matter of days), or over a longer period of time (such as a year or two). Studies which extend over more than one year are preferable, as they can capture the seasonal effects and changes that take place in the studied phenomenon over a reasonable length of time (Bhopal, 2008). Cross-sectional studies are able to provide data on different aspects of diseases, such as the medical history and risk factors (Bhopal, 2008). One of this design's limitations is that it identifies only the known participants; for example, it includes the participants on disease registers and does not include people who have the disease but are not yet diagnosed or recorded in the register (Bhopal, 2008). Similarly with some other designs the generalizability of this design is limited as a result of problems that may take place for example in sampling, and susceptibility to bias in reporting or analysis (Bhopal, 2008).

7.3 Study settings

The four public renal dialysis centres (RDCs) in the northern region of Oman were approached for data collection. These four RDCs were chosen for a number of reasons:

- The four RDCs together had around 28% (338 patients) of the treated kidney failure population in Oman (2012 census) out of 1,221 treated kidney failure patient on dialysis in Oman in 2012 (Ministry of Health, Oman, 2013).
- This part of Oman is the most densely populated area in Oman with Omani citizens (with a population of 700 thousands Omani in the 2012 census – The National Centre for Statistics and Information, 2013), so it was expected to be a representative population.

7.4 Study population and sample characteristics

The selection process began with the knowledge that the Oman had 18 RDCs distributed over ten governorates (Table 7-1). From the 2012 Oman's MOH annual report, the census of patients on dialysis was identified. The dialysis patients identified by the end of 2012 in the four dialysis centres that were planned to be approached for study two were as follows: 114 patients in the first setting (will be called RDC1), 41 patients in the second setting (RDC2), 69 patients in the third setting (RDC3), and 114 patients in the fourth setting (RDC4 - Table 7-1). Thus the total number of patients expected to be in the sample prior to data collection were in excess of 338 patients in the northern region of Oman.

Table 7-1 Oman's MOH 2012 statistics for dialysis population across RDCs

Governorate Name	RDC Name	No. of patients' on dialysis on 31 st December, 2012	% of patients
The north subdivision 1	RDC1	114	9.34
The north subdivision 1	RDC2	41	3.36
The north subdivision 2	RDC3	69	5.65
The north subdivision 2	RDC4	114	9.34
The capital	The central RDC	310	25.38
The capital	RDC5	25	2.05
The capital	RDC6	17	1.39
The west end of Oman	RDC7	36	2.95
The interior	RDC8	115	9.42
The interior	RDC9	25	2.05
The south	RDC10	125	10.24
The west	RDC11	54	4.43
The east subdivision 2	RDC12	46	3.77
The east subdivision 2	RDC13	44	3.60
The east subdivision 1	RDC14	50	4.09
The east subdivision 1	RDC15	25	2.05
The peninsula	RDC16	9	0.73
The peninsula	RDC17	2	0.16
10 Governorates	18 RDCs	1221	100%

Note that there are two governorates in the north (i.e. subdivisions 1 and 2); also two governorates in the east (i.e. subdivision 1 and 2); the west end of Oman is written in this manner to avoid the confusion with west end of other parts of the world like the West End of Glasgow. The RDCs highlighted in blue are the settings of this study.

This cross-sectional study covered all patients who underwent regular haemodialysis in four public sector dialysis centres in the northern region of Oman. For the cross-sectional study selecting a representative sample rather than an entire population was seen more realistic and less expensive (Polit and Beck, 2014). The most suitable sampling method selected for this study was non-probability sampling (Robson, 2013). The principle of selection was convenience sampling because all the registered patients (who were on regular dialysis sessions) in the four approached RDCs were considered as representative and convenient to approach. The northern region of Oman is considered to be representative of the Omani population because it is a large and densely populated area. In terms of Omani citizens, it is the most populated area of Oman, with 717,192 Omanis (Table 7-2), although when including non-Omanis the census population increases to over one million according to the census of mid-2014 (The National Centre of Statistics and Information – NCSI, 2015). In other words, it is the largest area, with the highest Omani population, and as a result the northern region's four renal dialysis centres (RDCs) served more than a quarter of the total dialysis population in Oman (28%) by the end of 2012 (Table 7-1). The sample selected was a convenience sample because it was convenient to include all the available patients on haemodialysis at the time of conducting the study in the northern region of Oman. The northern region of Oman is spread over a great length of Oman's coastline, with an area equal to 25 thousands km² (i.e. ~15.5 thousand miles). Due to its great size, it is therefore further sub-divided geographically and politically into two parts, which in this thesis will be referred to as subdivision 1 and subdivision 2. Each subdivision has two renal dialysis centres and covers all the population living in that subdivision (i.e. catchment area). The distance between each individual RDC and the other is not standardized (Table 7-2).

Table 7-2 The breakdown of Oman's population across regions and districts

© The National Centre of Statistics and Information/Oman, 2015 (statistics for 2014)

Variables	Omani	Non-Omani	Total	Distance from the main hospital to the named district in kilometres (km)
The northern region				
Subdivision 1 districts				*
District 7	19,357	4,324	23,681	68.9
District 8	13,120	2,923	16,043	~65
District 9	82,628	22,879	105,507	40.3
District 10	12,681	2,021	14,702	62.4
District 11	62,018	19,902	81,920	7
District 12	80,944	37,724	118,668	37.7
Total	270,748(37.8%)	89,773	360,521	
Subdivision 2 districts				**
District 1	106,941	90,576	197,067	4.2
District 2	94,892	39,079	133,971	28.7
District 3	51,073	14,192	65,265	64.3
District 4	29,400	11,496	40,896	35.1
District 5	53,897	11,983	65,880	59.6
District 6	110,241	42,103	152,344	96.7
Total	446,444(62.2%)	209,429	655,423	
Total (both subdivisions)	717,192(100%)	299,202	1,015,944	
* This is the distance from RDC1 which is located in District 11, to the other served districts; also the distance between RDC1 and RDC2 which is located in District 9, is around 40.3 km				
** This is the distance from RDC4 which is located in the District 1 hospital, to the other served districts; however, the distance between RDC4 and RDC3 (also located in District 1) is around 20 km				

In the northern region of Oman, the population of males (50.4%) is relatively higher than females (49.6%), according to the mid-2014 census (Table 7-3), and this was the general ratio found later on within the study sub-population.

Table 7-3 Census of Omani males to Omani females across age groups in subdivisions of the northern region of Oman

© The National Centre of Statistics and Information/Oman, 2015 (the statistics included are for 2014)

Variables	Males	Females	Total
<u>Subdivision 1(RDC1&2)</u>			
0-19	61,379	60,204	121,583
20-44	55,814	55,454	111,268
45-64	12,665	13,885	26,550
65-75	3,320	3,448	6768
>75	2,434	2,145	4579
Total	135,612	135,136	270,748
<u>Subdivision 2 (RDC3&4)</u>			
0-19	102,378	98,122	200,500
20-44	93,096	90,381	183,477
45-64	21,123	22,631	43,754
65-75	5,537	5,620	11,157
>75	4,060	3,496	7,556
Total	226,194	220,250	446,444
Overall Total	361,806 (50.4%)	355,386 (49.6%)	717,192 (100%)

The sub-populations served by the RDCs of subdivision 1 live in six catchment districts which are named in this thesis as District 7 to District 12 (Table 7-2). The total population living in subdivision 1 was 360,521, of which 270,748 were Omanis in mid-2014 (National Centre for Statistics and Information/Oman, 2015).

Subdivision 2 is composed of six districts, which are named as District 1 to District 6 (Table 7-2). The total population living in subdivision 2 was 655,423, of which 446,444 were Omanis in mid-2014 (The National Centre of Statistics and Information – NCSI, 2015). Note that part of the District 6 population is served by RDCs of Subdivision 1 because this district is very large and need more than two RDCs to serve its population.

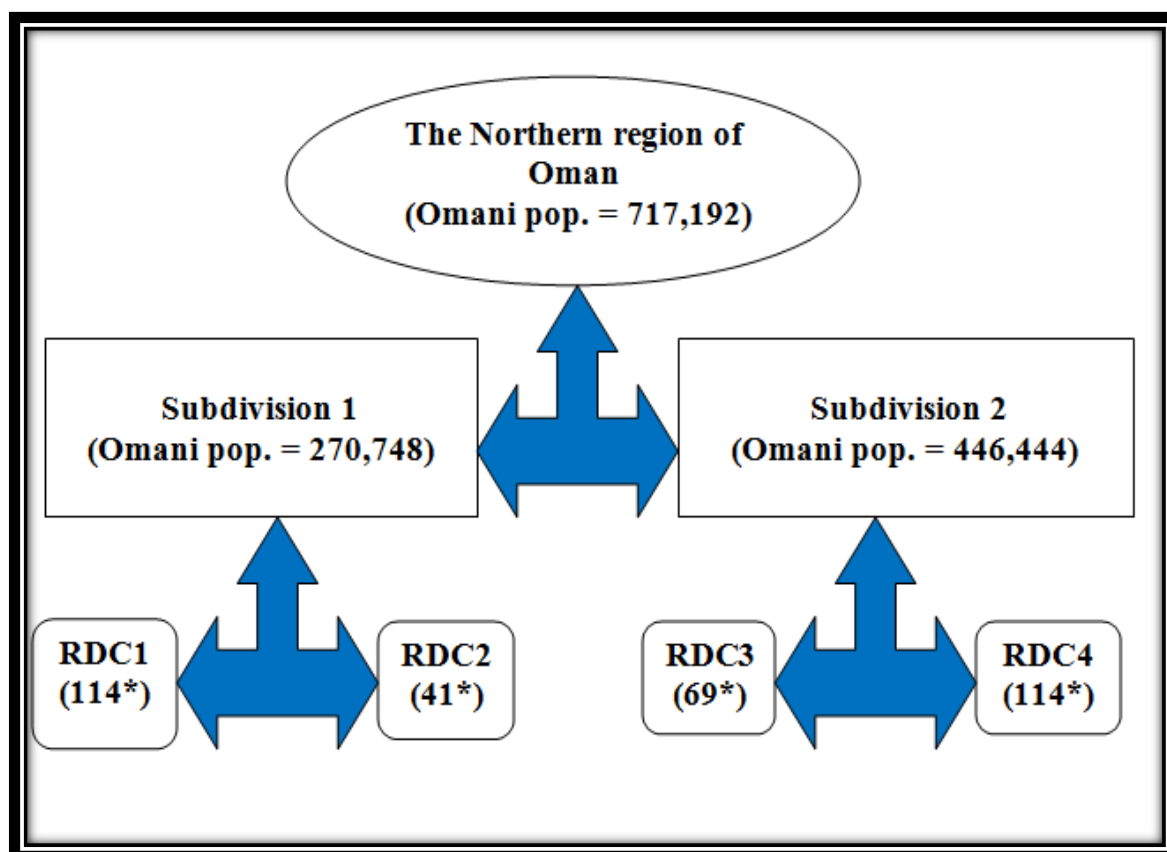


Figure 7-1 The Omani population of the northern region in relation to their RDCs sub-population

* This is the number of patients who were on dialysis by end of 2012

The target population was treated kidney failure patients on regular dialysis who were registered in any one of the four RDCs in the northern region of Oman. These patients had to undergo dialysis for at least three months in order to be identified as a definite kidney failure case according to the KDOQI definitions of CKD and kidney failure. The selected participants were Omanis because most of the expatriate population living in Oman were Indian or Bangladeshi and perhaps were included in their own countries' renal databases, so to avoid duplication and contamination of the study data non-Omanis were excluded (for further justification see 6.2 on p.118). At the time of the data collection, 380 people were on haemodialysis treatment in the northern region of Oman. Of these, 341 met the inclusion criteria (Figure 7-2). Inclusion and exclusion criteria were the following:

- **Inclusion criteria:**

1. Omani kidney failure patients (of any age) who live in the northern region of Oman.
2. On regular weekly dialysis for a minimum period of at least three months.

3. Registered as a dialysis patient in one of the four selected renal dialysis centres selected in the northern region of Oman.

- **Exclusion criteria:**

1. Had dialysis for less than three months.
2. Known to be dialyzing temporarily (e.g. acute renal failure following snake bite).
3. Non-accessible patients such as those who were not on regular weekly dialysis e.g. peritoneal dialysis (PD) patients and kidney transplanted patients.
4. Non- Omanis (expatriate)

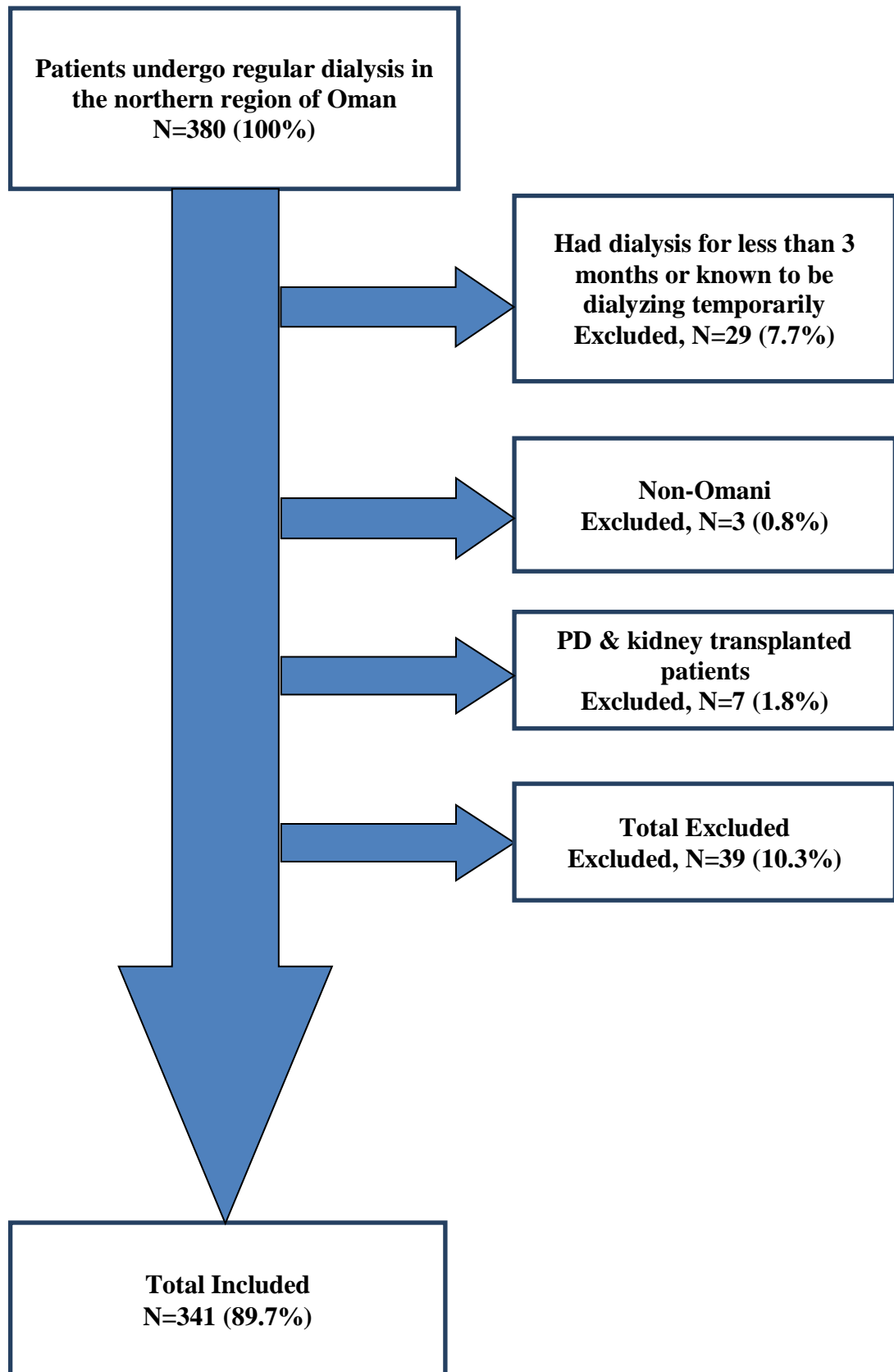


Figure 7-2 Included and excluded participants

7.5 Recruitment

After obtaining approval from the ethical committees of Oman and of the University of Glasgow to conduct this study, copies of the letters were taken by the author and given to the administration of the hospitals which the RDCs belonged to (i.e. RDC2 & RDC4), or to the person in charge of the RDC if the RDC was independent (i.e. RDC1 & RDC3). Permission from the hospital/RDC head was obtained verbally or in writing prior to approaching the participants. The RDC patient registers (with 380 patients) were inspected to identify the included (341) and excluded (39) patients. All the patients who complied with the inclusion criteria were recruited.

The RDCs had either two or three duty shifts, so participants were approached depending on their availability during the shift attended by author, according to pre timetable made by the author on the day one of being in the RDC. Generally the participants were approached during their dialysis sessions at the RDC. However, sometimes participants preferred to take the researcher administered survey during their waiting time prior to the dialysis session, because, for example, they had arrived too early for their dialysis sessions and preferred to utilise their waiting time to complete the survey and then sleep at the time of the dialysis. The participants' wishes were respected at all times.

The research information sheet was handed to the participants and/or authorized person and explained by the author (see Appendix D-1 and D-2 on p. 253 & 254). The participants and/or authorized person then signed the informed consent (see Appendix D-3 and D-4 on p. 256 & 257). Afterwards, the author administered the researcher administered survey either face-to-face (15-20 minutes long), if participant available, or later by telephone call if they had not been available until the last days for the author in that particular RDC. In the case of the telephone calls, the information sheet was explained verbally, the consents were taken verbally, and the participants were asked to sign the informed consent sheet as soon as they were back for dialysis in their RDC.

7.6 The study tool

Quantitative research is a structured and controlled approach, where the data is collected using a formal, unified tool, administered using the same approach for all patients (Polit and Beck, 2012). The tool in quantitative research provides a measurement of pre-

determined variables to eliminate the ambiguity of a studied health problem and provide a clear framework for data collection (Polit and Beck, 2012). The measurement outcomes provide precise information, usually in numbers, about such studied health problems. In this project's context, one major challenge was to develop a reliable and valid tool to measure the variables of this cross-sectional study. Polit and Beck (2012) suggest that the task of developing a data collection plan and tool involves a lot of creativity and choices, which implies the complexity of this process.

The tool developed for this cross-sectional study was a survey (see Appendix D-6 on p.263). The basic aim of the survey was to be able to gather data to assist in developing the first description of the characteristics of dialysis-treated kidney failure patients for the northern region of Oman. However, finding a ready-made validated survey tailored exactly to the purpose of this study was not feasible. This conclusion was reached after reviewing the literature and extracting similar studies, which used a tool similar to the one intended. One particular study conducted in Libya matched partially the aims of this cross-sectional study; however the tool was not published at that point of time and the Libyan author did not respond when contacted via email.

Polit and Beck (2012) acknowledge that designing a "well-developed" data collection tool is time-consuming, and cannot be fulfilled in a short time. Therefore finding a rigorously validated tool from another source such as kidney registries and renal databases was considered feasible. All reviewed renal registry and database surveys were designed to measure many variables when compared to this project's cross-sectional study. Therefore, items matching the aim of the cross-sectional study were extracted, slightly modified and re-used with maintainance of proper citation and copy right as indicated by each renal database. The process of building up the survey is explained step by step in the following.

7.6.1 Survey development process

The study tool was primarily a researcher administered survey. The survey had 61 items and was divided into five sections as follows: patient demographics, disease profile, risk factors at incidence, impact of kidney failure and dialysis on patient, and death profile (see Appendix D-6 on p.263).

As explained earlier, the survey items were extracted, slightly modified and re-used from different renal registries and renal databases. Three sections from the survey (i.e patient demographics, disease profile and death profile) were derived primarily from three renal survey forms. The first two forms were from the “centres for Medicare and Medicaid services or CMS forms”. First one called “ESRD medical evidence report Medicare entitlement and/ or patient registration”, and the second one called “ESRD death notification”, available for public and researchers via this link on the USRDS website: http://www.usrds.org/2015/appx/4_CMS_KF_Forms_15.pdf (for copy right permission, see p.248). The third form (called “kidney dialysis patient survey”) was from the “annual audit census for haemodialysis”, available via the Scottish Renal Registry website link for SRR Projects A-Z: <http://www.srr.scot.nhs.uk/Projects/PDF/2014/May-2014-Census-HD-Form.pdf?1> (for copy right permission, see p.248). The section on the ‘risk factors’ was derived and based on the author reading for the Taal and Brenner (2006) article on “predicting initiation and progression of chronic kidney disease: developing renal risk scores” (see Reference list on p.225). The section on the ‘kidney failure impact on participants’ QoL’ was derived from the kidney disease and quality of live (KDQOL) survey (KDQOL-SFTM 1.3) which is available on http://www.rand.org/health/surveys_tools/kdqol.html (for copy right permission, see p.250).

The patient demographic section contained variables such as residence, date of birth, gender, race, marital status, education level and occupation. The disease profile section identified variables such as the primary disease (i.e. the first chronic disease the patient got in his life, mainly looking for diabetes, hypertension and cardiovascular disease), investigations done at that time to diagnose kidney failure, present co-morbidities at the time of data collection, dates of first diagnosis with kidney failure and first dialysis date, dialysis modality type, vascular access type, and kidney transplantation plan. The risk factor section had 21 listed risk factors, including the presence of diabetes, hypertension or intake of nephrotoxins; the participant was asked if any of these risk factors were present prior to the first diagnosis of kidney failure (see Appendix D-6 on p.263). Section four was measuring the impact of kidney failure. It comprised of four variables; namely kidney failure interference with the patient’s life, feeling of being a burden on family or community, if having any frustrations and worries, and any effect of kidney failure on the patient’s financial income. The final section of the survey was used to record the death profile of the patient, and this included variables such as the date of the patient’s death,

cause of death, and age of the patient at death. This last section was completed if the participant died during the data collection phase, which began in October 2014 and ended on 31st December 2015.

Most of the items of the survey had predetermined dichotomous answers (yes/no responses - Figure 7-3). A few questions were considered open-ended questions, which mean they needed a written answer: either a date (e.g. date of birth) or a short description (free-text question), as with the question ‘What do you think is the cause of your kidney failure?’

4. Date of Birth:	<input type="text" value=".... / /"/>	(Day / Month / Year)		
5. Gender:	<input type="checkbox"/> 1.Male	<input type="checkbox"/> 2.Female		
6. Nationality:	<input type="checkbox"/> 1.Omani	<input type="checkbox"/> 2.Non-Omani		
7. Ethnicity or Race:	<input type="checkbox"/> 1.White	<input type="checkbox"/> 2.Black	<input type="checkbox"/> 3.Asian	<input type="checkbox"/> 4.Other
	Specify Other:			
8. Marital Status:(If the answer is ‘divorced’ then go to the next question and if the answer is the other three then go to question number 10):	<input type="checkbox"/> 1.Single	<input type="checkbox"/> 2.Married	<input type="checkbox"/> 3.Divorced	<input type="checkbox"/> 4.Widowed
9. If you are Divorced, is it because of your sickness with ESRD and being on dialysis:	<input type="checkbox"/> Yes	<input type="checkbox"/> No		
10. Education level:	<input type="checkbox"/> 1.Illiterate	<input type="checkbox"/> 2.Read & Write	<input type="checkbox"/> 3.Primary (1-9)	
	<input type="checkbox"/> 4.Secondary (10-12)	<input type="checkbox"/> 5.College	<input type="checkbox"/> 6.Post-College	
11. Occupation: (If the answer is <u>Yes</u> go to question 13 and if <u>No</u> go to the next question):	<input type="checkbox"/> 1.Yes	<input type="checkbox"/> 2.No		

Figure 7-3 Capture of one part of the survey

Finally, some of the concepts in the survey were believed to be by some means ambiguous and needed some sort of explanation to avoid confusion. For example, with the variable “parent dialysis unit”, which meant the dialysis centre where the participant is registered to undertake his/her favourite regular dialysis sessions, and which usually served the catchment area where the participant live in.

Another variable was “race or ethnicity”, which was a difficult term to define because in Islam, the religion of most Omanis, all people are to be considered equal and it is

prohibited to categorize people based on their race/ethnicity. However, the idealism that Islam and most religions of the world call for is not always the reality. The reality is that most Omanis have the concept of race/ethnicity in their minds and sometimes speak out loud of how they think this concept should be defined. Omanis see race/ethnicity as either: White (people with fair skin and not Mongolian -Mongolian in this context indicating Chinese-like physical features such as flatter faces and smaller noses), Blacks (people with black or dark skin, very curly hair, wide noses, and not Mongolian), Asians (typical Omanis, with a skin colour in between white and black, and not Mongolian), and others (people who do not fit in any one of the above categories). This latter race/ethnicity categorisation was the ones followed in this study survey.

Also, the meaning intended by the author for the variable 'urban' was to mean the highly populated cities, with good infrastructure and a high rate of employment; and 'rural' to mean the less populated places with developing infrastructure and low rate of employment. Any option that did not fit into these two categories (urban or rural), were identified as 'mixed', meaning they have features of both urban and rural environments, or cannot be identified.

Another issue is that some participants had a history of failed or sometimes recurrent failed renal transplantation. This means that those participants were returned to dialysis, so for such participants, the history collected was of the current dialysis while interviewing them and not for the previous dialysis. For example, if the participant was on dialysis in 1995 and then managed to have a successful kidney transplantation and was off dialysis for five years, but thereafter the transplanted kidney failed in 2000, and as a result he or she was on dialysis again until surveyed by the author. In such a case the date of 1st dialysis recorded for this participant was 2000.

Another concept to clarify is "primary diagnosis", which is defined in this study as the first chronic disease the participants had first in their life, and mainly looking for diabetes, hypertension and cardiovascular diseases. Also, "limited access to RRT" refers to those who live in the mountains or places far from her/his parent RDC, or those with no nearby RDC serving her/him, or with no access for dialysis secondary to such reason, who therefore do not attend the dialysis sessions frequently. The final concept is "health care beliefs", defined as any personal beliefs a patient has which influence her/his attitude towards health, usually negatively.

7.6.2 Justification of survey selection

Across the literature, there is a consistent association between cross-sectional studies and surveys. In most of the descriptive cross-sectional studies or most descriptive research, survey is the primary tool for data collection (Public Health Action Support Team – PHAST, 2017; IARC, 2017). The main aim of survey is to determine the current status of a phenomenon or a situation (Public Health Action Support Team – PHAST, 2017; International Agency for Research on Cancer - IARC, 2017). Survey helps to collect data such as demographic, socio-economic, health characteristics of population and to estimate specific parameters in a population such as prevalence, and to describe association between different variables (e.g. in between gender and age – (Public Health Action Support Team – PHAST, 2017; IARC, 2017).

However, selection of the survey should be based on the research question (Diem, 2002). In other words the survey should be the best method to answer the research question of a research project. For this cross-sectional study (i.e. survey research) there were two main research questions (see cross-sectional study research question on p.133). For the first research question, the survey was the best tool to gather data on variables measured by that question such as demographics and disease characteristics. These variables are quantitative and can be captured best by a survey tool rather than focus groups or semi-structured interviews which are most common tools in qualitative research.

For the second research question, focus groups or semi-structured interviews were possible data gathering alternatives. This research question intended to have an initial measure only on absence or presence of negative impacts on the QoL of the participants of this study. Therefore, the predetermined dichotomous answers (yes/no responses) were used to identify the absence or presence of the impact. However, QoL is frequently explored in the literature by qualitative methods. On the other hand, the author selected a quantitative approach to answer this research question, and this was due to number of reasons. First, the author wanted only to determine the absence or presence of the negative impact on the participants. Subsequently, this determination will identify the size of population having negative impacts. Thereafter, it will be known if the answer to this research question is compatible with the global findings in order to make the suitable recommendations for the best research method to explore this aspect further. Second reason, the author is aware of the availability of disease-specific QoL tools such as KDQOL-SFTM. This tool was

developed to track kidney disease patients' views about their health, about their feelings, and about their ability to maintain good activity of daily living . Also, this tool measures the burden of advanced kidney failure on patients using rating scale and not predetermined dichotomous answers (yes/no responses - Research and development – RAND, 1994-2017). This tool is used by many scholars to mainly measure the QoL scope solely. However, this study is not solely exploring QoL , but other aspects such as the presence of what risk factors existed prior to the occurrence of kidney failure. Yet assessment of quality of life can be controversial, it needs more than fixed response questions that are used in this study. It needs a separate and focused study using disease-specific QoL questionnaires. However, it was not intended at this stage of this research to focus on QoL . Also the tool for this study (see Appendix D-6 on p.263) had to be short because it was designed to be administered by the author during a researcher administered survey, usually with sick patients. It was essential and ethical to consider the tolerance of patients with chronic illness for questioning, which is usually low. Iarossi (2006) suggests that higher response errors can take place if the questionnaire is long and overloads the participant's time and memory. Therefore the items on QoL utilised closed questions rather than open. Finally, due to the tied timelines of this research study, having more than 300 patients, it was not feasible to explore their QoL in depth at this stage.

7.6.3 Validity of the survey instrument

The reliability and validity of any data collection tool are based on the internal quality of the data collection form and the degree of measurements the data collection tool is taking for the variables included in the research question (Polit and Beck, 2012). Reliability concerns the accuracy of data collected. The accuracy of the data collected in this research was ensured by first gathering the data from the primary source, that is, the patients; and secondly by verifying the accuracy of the patients' answers by comparing them with additional sources such as patients' medical records. Another reliability check on overall answers was performed by the author before and during data entry into the SPSS programme, to ensure the answers were coherent prior to the analysis stage (Iarossi, 2006). The survey (see Appendix D-6 on p.263), used in this research is believed to be of a good standard because it was based on evaluated surveys which were tested and retested by some of the international registries and databases of the world. Additionally, this study survey was evaluated by a panel of experts. Furthermore, the survey was tested during the pilot study, and a revised version was made thereafter. All the details of the survey's

creation and amendments are described further under the study tool section (see section 6.6, p.144).

The survey was the instrument used to gather the data for this study. The quality of any research depends on the quality of the instrument used. One important measure to assess the quality of a quantitative study is the reliability measure, which simply means measuring the accuracy of an instrument to ensure the rigour of the gathered data (Heale and Twycross, 2015). It is difficult to give precise calculation of reliability of an instrument; however an estimate can be achieved by testing three major attributes of reliability. These attributes are homogeneity (internal consistency), stability (consistency of the results) and equivalence (consistency among the responses of participants). The internal consistency of an instrument can be tested using different statistical tests such item-to-total correlation, split-half reliability, the Kuder-Richardson coefficient and Cronbach's α ; the latter is the most popular test (Heale and Twycross, 2015). The stability of an instrument is assessed through the use of common test-retest measurements, which means giving a test score each time the instrument is completed by a sample participant, and repeating this procedure more than once under similar circumstances (Heale and Twycross, 2015). A statistical comparison is then made between the scores, to give an indication of the stability of the instrument. The equivalence attribute is measured via inter-rater reliability, which is a process whereby two or more describers test the same instrument and each give a score for that same instrument. The agreement between scores given by these describers can indicate the equivalence of the instrument, and enhance the reliability of the instrument.

In this study, testing of the internal consistency, stability, and equivalence of the survey were not undertaken. However, the reliability of the instrument was ensured by other different strategies. First of all by the fact that most of the items used in this study survey were derived from trusted international renal registries and databases which are considered high quality clinical databases. For example, USRDS functions through a trusted steering committee and external expert panel which collaborate to ensure the best quality established tools are used and best quality data analysis are undertaken (United States Renal Data System – USRDS, 2016). Secondly, the author was the one asking the survey's questions, and at the same time recording the participants' responses, rather than relying on research assistants - in order to reduce the risk of bias and conflicts in recording responses. Thirdly, the same structured survey was used for all participants, including the

same questions and following the same instructions, to maintain equivalence. Fourthly, the author did not involve other researchers in this process, so that the way the questions were asked and explained was consistent, and also to ensure that the intention behind each question was fully conveyed to the participants in a consistent way, that the responses recorded were the right ones for the relevant question, and also to ensure that those surveyed fit within the sampling frame of this study. Finally, the instrument was examined for any shortcomings in the pilot study. Despite all of this, no researcher can claim to have achieved 100% reliability, because of issues like participant error or bias, and describer error or bias (Robson, 2013). Furthermore, there are also some disadvantages to researcher administered survey, such as the high cost, and the difficulty in asking sensitive questions while facing the patient (Robson, 2013).

Another criterion by which to judge the quality of data is by ensuring the validity of the instrument by making sure it measures what it is supposed to measure (Polit and Beck, 2012; Robson, 2013). There are three main types of validity, which are content validity, construct validity and criterion validity (Heale and Twycross, 2015). Content validity examines to what degree the instrument measures the research variables (Heale and Twycross, 2015). Construct validity inspects the level to which the instrument measures the desired construct of the research (Heale and Twycross, 2015). Finally, criterion validity describes the extent to which the instrument is related to other instruments that measure the same variables (Heale and Twycross, 2015). Validity is difficult to measure because there is no ready-made equation or test to calculate the validity of an instrument (Polit and Beck, 2012). However, triangulation can be helpful in this regard, using multiple sources of data to ensure that the data collected was accurate (Robson, 2013, p.158). Although the author used multiple sources to gather the information as explained earlier but the author did not undertake formal triangulation. For this study, the instrument used did measure what it was supposed to measure, and the data was gathered from multiple sources, that is, as far as possible, from patients, patient records, and the renal team caring for those patients.

Most of the participants (n = 334, 98%) were present at the RDCs to undertake the researcher administered survey. The participants who were not available but matched the inclusion criteria were telephoned; seven (2%) participants had telephone interviews. The data regarding the death profile of the surveyed participants was followed up passively, so one core member of the renal staff was selected during the active phase of the data collection per RDC to assist in sending the information relevant to the death of any

participants directly to the author. A default date was set per month (5th of the month) as a reminder to ask for any data available from the selected staff member. Moreover, the author re-visited the study settings during the passive period to complete the data for death profiles and double-check the accuracy of the information sent by the core staff member.

7.7 Data collection process

The process of data collection started after obtaining ethical approval of the study. The four data collection locations were visited consecutively by the author. The information sheets were distributed on the day one for the first half of the participants and on the day two for the remaining participants. Additionally the information sheet was explained verbally for most patients on an individual basis because most of them were illiterate. All volunteers to participate were informed about the research and then they signed the consent sheet before filling the survey. The researcher administered survey was used for all the participants and completed by the researcher herself. The primary source of the collected data was the participants. However all relevant survey data that could be counter checked with their medical records were checked after taking the participants' permission especially if the patient could not give specific answers such as the date of the first dialysis. The participants' permission was obtained verbally to access their medical records as this access was not clearly highlighted in the written informed consent and in the information sheet because this was not seen practiced in the clinical settings of Oman. However, the process of seeking data from the participants' medical records were explained and mentioned clearly in the proposal, which was approved by the ethics committees (see Appendix A-4 on p.247). Human participants in research must understand about the research they are involved in and they should freely accept participation (The Royal College of Nursing - RCN, 2011). However, the inclusion of access permission in the informed consent and information sheet was the best recommended to reassure that the participant is best informed and the researcher is legally and ethically protected. Also, the participants' data if not found in participant's medical record were collected from the assigned staff if possible (for more specification on the sources of the collected data see Figure 6-1). Also items 59 to 61 were filled up only if the participant died during the data collection phase.

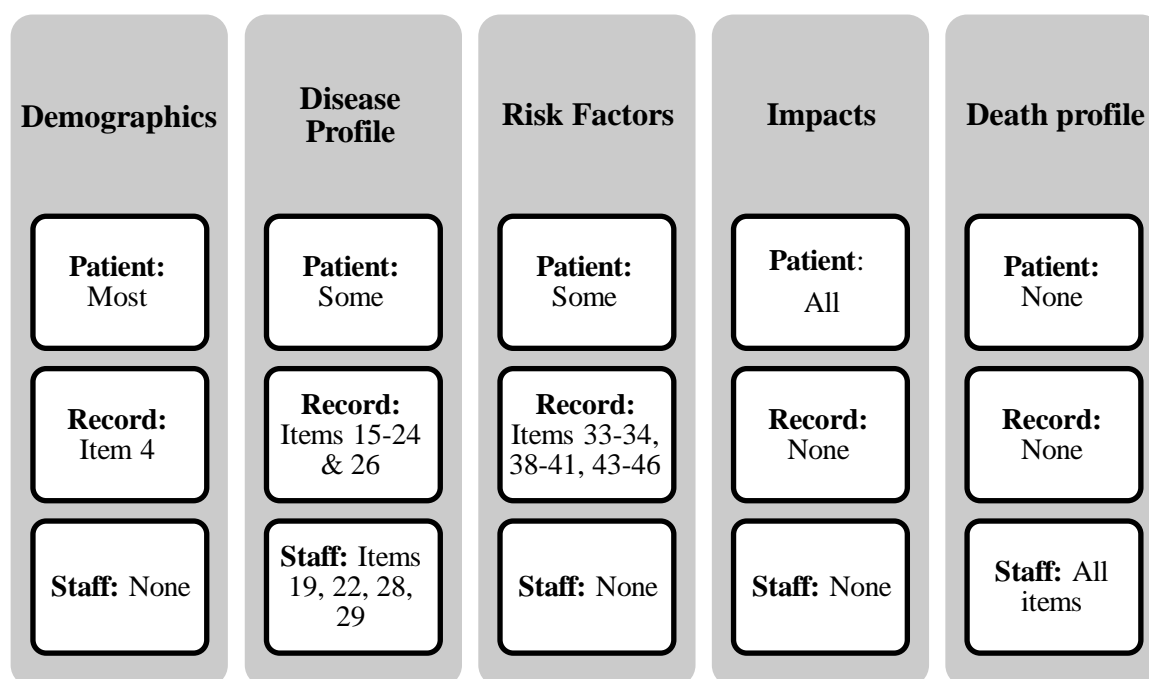


Figure 6-1 Sources of the collected survey data

7.8 Ethical considerations

All included participants were handed an information sheet in Arabic (see Appendix D-1 and D-2 on p.253-254) and in case the participant was not able to read, the information about the research was explained verbally to ensure the participants' understanding. The participant and/or authorized person then voluntarily signed a written informed consent (see Appendix D-3 and D-4 on p.256-257). Also the medical records for the patient were accessed after taking verbal consent. (See section 6.7 on p.151, for details of the verbal consent and approval from the participants). The permission to access the patient's medical records were obtained from MOH earlier as this was explained in the proposal approved by the ethical committees of MOH and UOG (see p.247) the participants had the right to accept or reject participation, or withdraw at any time of the study. This was explained to them. For vulnerable participants, such as children (in Oman adults are those aged 18 and above), the consent was taken from the responsible/authorized person. If any participant had any queries, they could ask before beginning or at any time during or after the interview. All participants were treated with equal respect, fairly, and their rights to privacy were safeguarded at all points in this study. The participants were not exposed to any potential risks during the time of data collection, the benefit of the study was explained to the participants, the participants were selected fairly and accepted participation

voluntarily, and all the necessary measures were taken to protect privacy and confidentiality for the participants (Beauchamp and Childress, 2009). Therefore, this study satisfied the principles of biomedical research ethics.

The survey forms were kept secure during the data gathering stage and afterward were stored securely in a locked cabinet, within a locked room at the University of Glasgow. These forms and all relevant confidential documents will be destroyed after ten years of retention as per University of Glasgow policy of “data management and support for researchers” which is available at this link: <http://www.gla.ac.uk/services/datamanagement/storageandcosts/>. The data entered into the statistical analysis package was anonymous and completely coded.

7.9 The pilot study

The pilot study was undertaken prior to the main study and after receiving ethical approval. This was essential in order to determine if any part of the study required amendments. The general guideline on the size of the sample required for a pilot study is using 10% of the sample required for a full study (Hertzog, 2008). For this research, the estimated full study sample was around 400 participants, and accordingly 40 participants were adequate as a sample for the pilot study. However, the author approached one dialysis centre that estimated to have 40 patients, but on field visit, there were 47 participants who satisfied the inclusion criteria. Consequently, the structured survey was administered by the author with 47 participants (about 14 % of the actual sample). The pilot interview sample was kidney failure patients under regular haemodialysis, but selected from a geographical area different from the main study settings. At the pilot RDC, comments about the clarity of the survey, its logical flow, missing items, extra items, the burden of questioning, any offensive questions, and the actual time needed to complete the survey were considered.

Thereafter, some amendments were made to the original protocol. The required amendments were minor, except one, which was the addition of telephone calls to the methods. The main data collection method was researcher administered survey, but on a few occasions some of the patients were not available at the pilot RDC during the active data collection period, for example when a patient was admitted to another hospital and could not be reached. So it was feasible to add the telephone call in order to contact such patients who were interested to participate in this research study but could not attend the

RDC. The author agreed with the telephoned participants to leave the study information sheet and the participant informed consent with their assigned staff nurse so it could be handed over to them whenever they were next in the RDC. Also, after the informed consent was signed by these participants, the author was informed, in order to collect them. The main amendments took place in the survey were as follows:

- Some of the sentences in the original protocol on how to approach the participants were rephrased and expanded to make them more explicit, to give step-by-step guidance to the author (e.g. more detail on when and where to approach the patients for interviews).
- The numerical coding for the survey was amended to be alpha-numerical, which was found to be more explicit to use, in order for the author to be able to identify not only the participant but also the participant's RDC later on, if needed.
- Two exclusion criteria were added to make clear identification of the population.
- The consent form was amended to permit an authorized person to sign it on behalf of a vulnerable participant if needed.
- Some amendments were made in the survey's items to enable easy entry and analysis on SPSS software, e.g. redundant items were removed and more explicit coding and numbering were made, and also the general outline of the survey was made more organised and fluent.

All the necessary modifications to the original protocol were carefully made, the protocol was resubmitted to the ethical committees, and all the necessary approvals were given for the second time (see Appendix-A on p.244-246).

Meanwhile, the main results from the pilot study were not included in the analysis of the main study but reported in this section as follows. There were 47 participants who had a definitive diagnosis of kidney failure and were on dialysis at the time of data collection. There were 32 males (68.1%) and 15 females (31.9%). Nineteen participants reported that they were illiterate (40.4%), 12 had a secondary education (25.5%), seven had a primary education (14.9%), five participants did not follow formal education but could read and write (10.6%), three had a college education (6.4%); and one participant had a post-college education (2.1%). About two thirds of the participants were without jobs (76.6%). Almost 90% of the participants reported having diabetes or hypertension as a primary disease: 46.6% diabetes and 43.1% hypertension. Most of the participants (70.2%) reported that

dialysis had not caused them stress or worry, and that it had little financial impact on their lives.

7.10 Preparing the data for analysis

The process of data preparation for analysis comprises checking, editing, coding, assembling, and transforming (Kent, 2015). The surveys were first checked for their usability after completion. Kent (2015) identifies unusable surveys by the pattern of responses: if the responses show some discrepancies, perhaps because the participant did not understand the question or the survey was completed by a non-member of the study population (such as non-kidney failure participants), the survey is weighted for its usefulness, and if shown to be unusable the survey is discarded. Upon collection of the inclusion and exclusion criteria, seven participants who matched at least one exclusion criteria were excluded, leaving 341 participants. In other words, the author identified 380 (100%) participants on dialysis at the data collection time, 32 (8.5%) were excluded on the spot and seven (1.8) were excluded later, at the checking phase. The numbers of eligible, usable surveys were 341 (89.8%).

The editing phase is the process undertaken to verify the consistency and accuracy of the responses (Kent, 2015). For this study, the accuracy of the responses was checked in the field by verifying the data obtained from the participants with their medical records. In a few instances some discrepancies were identified, such as the first dialysis start date. So in such cases the response was verified by the staff assigned to that participant, either at the time or whenever the staff member was available. If the data was successfully verified it was recorded, and if not, then it was labelled as missed data. Also, some inconsistencies were identified in the responses of a single participant. All the inconsistencies, which were minor, were corrected. Those which could not be resolved were treated as missing values. However, there was little missing data in this project overall (Table 7-4).

All items on the survey were pre-coded prior to the data collection being initiated, except for the multi-response items which were coded later during the data entry phase. Each response from the multiple responses was entered as a separate variable (Figure 7-4). Also, some of the open-ended questions were coded when possible.

17. Co-Morbidity: 1.Diabetes 2.Hypertension 3.DM & HTN
 4.Genetics 5. Cardiovascular 6. Vascular disease
 7.Other Specify Other:

ComorbidityD iabetes	ComorbidityH ypertension	ComorbidityD MandHTN	ComorbidityG enetics	ComorbidityC ardiovascular	ComorbidityV ascular
2.00	1.00	2.00	2.00	2.00	2.00
2.00	2.00	1.00	2.00	2.00	2.00
2.00	2.00	1.00	2.00	2.00	2.00
2.00	1.00	2.00	2.00	2.00	2.00
2.00	1.00	2.00	2.00	2.00	2.00
2.00	1.00	2.00	2.00	2.00	2.00
2.00	2.00	1.00	2.00	2.00	2.00
2.00	1.00	2.00	2.00	2.00	2.00
2.00	2.00	1.00	2.00	2.00	2.00
2.00	2.00	1.00	2.00	1.00	2.00
2.00	1.00	2.00	2.00	2.00	2.00
2.00	2.00	1.00	2.00	2.00	2.00
2.00	2.00	1.00	2.00	2.00	2.00
2.00	1.00	2.00	2.00	2.00	2.00
2.00	2.00	1.00	2.00	1.00	2.00

Figure 7-4 Example of a multiple response question

*The top is a multiple response question captured from the survey; the bottom is how the same question been entered as a separate variable in the SPSS soft ware

Usually researchers develop a codebook for the assistant researchers. The codebook may contain further details about the variables, further definitions or descriptions, or specific guidelines necessary for the same manner of data collection to be followed by all the research assistants (Kent, 2015). In this case, the author was the one who administered all the surveys. Also, a key document was developed to provide the necessary explanation whenever needed. This worked as a key reference to sufficiently remove any vagueness of terms or questions. For example, on the first page of the survey there was the term “parent dialysis unit”, so a note was written beside it to clarify what exactly was meant by this term.

Kent (2015) defines ‘assembling’ as the step that comes after the checking, editing and coding, and which consists of assembling the data from all forms of record, such as surveys and diaries, and entering them into the data analysis software. This study data was assembled into the Statistical Package for Social Sciences version 22 (IPM SPSS, Chicago,

IL). The data was subject to double-entry validation - which means that the data was entered twice by the author - and it was checked a third time by a peer reviewer. The peer reviewer had anonymised samples of data to check their entry, and thereafter the author had a final check on the data entered.

Although there was no transformation undertaken, but some categorisation or re-grouping of the variables was performed, for example re-grouping “date of birth” into five sub-groups of age, in order to create fewer categories for the many variables responded, and enables comparison afterwards. The general rules used in handling the data on SPSS were as follows:

- **Aims/objectives of the analysis**

Firstly, the data analysis should describe the sample population as a whole. Secondly it should compare data across the sub-divisions or RDCs, and thirdly, it should compare data (i.e. sample population characteristics) from this study with the evidence available from the literature.

- **Handling of missing data and the “do not know” responses**

In the case of this project, most of the ‘do not know’ responses were received when one of the following happened: firstly, when the participant was not able to remember certain dates, such as the date of the first dialysis and also the date was not found in any other resource, and secondly, when there were discrepancies between responses and it was impossible to verify the correct answer. Consequently these types of responses were recorded as missed data.

Some of the SPSS system’s missing data occurred as a result of the survey design itself (Table 7-4). For example, there was one item asking about the marital status of the participant. If the participant answered ‘divorced’, then he or she had to go to the next sub-set question, and if not divorced the participant had to skip the next sub-set question. So all the skipped questions, the system then recognised them as missing values (Figure 7-5). However, in one specific instance, a participant who was divorced refused to answer the sub-set question regarding divorce, and therefore this particular case was coded as an “item-non-response” or “user-defined missed value” rather than “system missing value” (Kent, 2015).

Table 7-4 Summary of missing data on SPSS

Type of missing data (items with missed data)	N**	%	Rationale
A.SPSS system missing values *9. If you are divorced, is it because of your KF & dialysis? (One participant refused to respond).	320***	93.8	All the listed questions were conditional questions (sub-sets), which meant that the participant had to answer them if s/he satisfies the condition required for that question/item
*11. If you have no occupation, is it because of your KF & dialysis?	49	14.4	
*29. If yes, when were you transferred from another RDC to this RDC?	333	97.7	
*31. Had you any failed renal transplantation?	309	90.6	
2.User-defined missing values *17. Co-morbidities *33. Risk factor: proteinuria *41. Risk factor: dyslipidaemia	18 34 4	5.3 10 1.2	Participants do not know and data could not be found
* serial numbers of items on the survey ** number of missing data values *** 319 system missed values and 1 user-defined missed value KF, kidney failure; N, number; %, percent; RDC, renal dialysis centre			

		Place Of Residence	Parent Dialysis Unit	Name of the RDC, the participant is dialyzing in at present	AgeGroup	Gender	Nationality	Ethnicity or Race	Marital Status	Are you divorced because of ESRD
N	Valid	341	341	341	341	341	341	341	341	21
	Missing	0	0	0	0	0	0	0	0	320

Figure 7-5 Example of SPSS system missing values

Kent (2015) recommends that if an item's non-responses are more than 5%, then the author can use certain techniques to resolve the problem, for example 'explicit imputation', where the missing values will be replaced by other actual values such as the mean of that response. However, the non-response rate in this project for most items was less than 5%, so it would not affect the results of the data analysis and there was therefore no need to use such techniques.

Regarding the entry of dates in the SPSS, the SPSS software requires the date to be entered in the form of day, month and year, and while participants usually remembered the years, they might not have remembered the exact month or date. Therefore, whenever necessary, the date was rounded off to the nearest convenient value for the participant's dialysis

history, if agreed by the participant. The final issue in this regard is that most of the participants' dates of birth were recorded as the 1st of January, which implies that the health agency's medical records computed the 1st of January as a default date. This may have happened because participants were not carrying their birth certificate and/or could not recall the exact date of birth while registering at the health agency. Nevertheless, this issue occurred prior to receiving the data and therefore the data was recorded as received. However, if participants were certain about their accurate date of birth, then the recorded date of birth was the most reliable or accurate one according to the participant.

Open-ended questions (free-text) can also be a source of missing data if the responses are not categorised and coded in the ideal way (Kent, 2015). In this study, the last question in the fourth section of the survey was an open-ended question, as the participants were asked about their thoughts on the cause of their kidney failure, and there were many responses recorded. The described pattern of answers was that most of the participants identified the cause as either diabetes combined with other reasons, or hypertension combined with other reasons, or both diseases, either singly or combined with other diseases. This was difficult to categorise and code, so it was left as it is and the analysis was carried out manually.

- **Statistical methods - descriptive statistics**

A profile of the sample population was computed using descriptive statistics on the SPSS version 22. The mean, standard deviation (SD), median, and 25th and 75th percentile were calculated for continuous data (e.g. age based on date of birth). N and % have been provided for categorical data (e.g. overall number and % of participants undergoing dialysis).

For nominal data, and where data was categorised or re-grouped - for example, when age has been measured at the continuous level but then categorised (i.e. in age groups) - a chi-squared test was computed for comparisons between groups, or a Fisher exact test was computed if the total number of observations was less than twenty or any of the expected frequencies were less than five. Comparisons between groups were made using two sample t-tests or non-parametric equivalents (i.e. non-normally distributed data; Mann-Whitney U test), or parametric (i.e. normally distributed data; one-way ANOVA test) in comparing continuous variables between groups based on the distribution of the data. An appropriate univariate type of analysis was carried out according to the needs as follows:

- To test the relationship between two categorical variables, a chi-square test or Fisher's exact test was carried out.
- To test the relationship between one categorical variable of two levels (e.g. gender) and one continuous variable (e.g. age) a t-test was carried out, because the data was normally distributed.
- To test the relationship between one categorical variable of more than two levels (e.g. education levels) and one continuous variable (e.g. age), a one-way ANOVA analysis was performed, because it was normally distributed data.

Comparison was made between subdivisions and/or between RDCs, between districts, between genders, between race/ethnicity, between marital statuses, between education levels, and between employments whenever seen as significant. The decision for statistical significance was based on the alpha value (α) of 0.05 significance level, and the null hypothesis was rejected if alpha was less than 0.05.

8 Results of study two

8.1 Overview

The following section presents the details of this study's results, and is structured under the following sub-headings: participant demography and characteristics, participant distribution across districts, participant perception on the risk factors, participant primary diseases and causes, participant co-morbidities profile, participant haemodialysis characteristics, participant perception on the impact of dialysis treatment on their lives, participant death figures in 2014 and in 2015, and participant plans on kidney transplantation. The reported results satisfy one main aim, which is to develop the first description of the characteristics of dialysis-treated kidney failure participants in the northern region of Oman.

8.1.1 Participant demography and characteristics

The overall age across the subdivisions and across the RDCs was normally distributed. The average age for this population was 51.7 ± 15.8 (mean \pm SD) years old, and the median was 54 years old (Table 8-1). The participants in subdivision 2 were slightly younger (mean age $M = 50.6$ years, $SD = 16.3$), compared with subdivision 1 ($M = 52.9$ years, $SD = 15.3$). However, when the mean age across the four RDCs is compared, RDC1 ($M = 51.9$ years, $SD = 15.9$) and RDC3 ($M = 51.3$ years, $SD = 15.5$) had almost the same mean age, while RDC2 appeared to have a slightly older population ($M = 55.6$ years, $SD = 13.3$) and RDC4 had a slightly younger population ($M = 50$ years, $SD = 16.9$). Statistically, there was no significant difference between the mean ages of the subdivisions (p-value of t- test, $P = 0.177$) and across the RDCs (p-value of one-way ANOVA test, $P = 0.282$).

Table 8-1 The statistical summary of the age variable across the northern region of Oman

Variable	All	Subdivision 1			Subdivision 2		
	Total (n=341)	All (n=167)	RDC1 (n=123)	RDC2 (n=44)	All (n=174)	RDC3 (n=77)	RDC4 (n=97)
Age							
Mean (SD)	51.7(15.8)	52.9(15.3)	51.9(15.9)	55.6(13.3)	50.6(16.3)	51.3(15.5)	50(16.9)
Med.(Q1,Q3)	54(41,63)	55(42,64)	54(41,63)	57(46,65)	53.5(38,62)	54(38,61.5)	53(37,62)
Mini.(max.)	10(94)	16(94)	16(94)	21(93)	10(84)	20(84)	10(83)
Age groups							
0-17 n (%)	6(1.8)	1(0.6)	1(0.8)	0(0)	5(2.9)	0(0)	5(5.2)
18-45 n (%)	102(29.9)	49(29.3)	39(31.7)	10(22.7)	53(30.5)	27(35.1)	26(26.8)
46-64 n (%)	164(48.1)	79(47.3)	57(46.3)	22(50)	85(48.9)	37(48.1)	48(49.5)
65-75 n (%)	52(15.2)	30(18)	19(15.4)	11(25)	22(12.6)	8(10.4)	14(14.4)
>75 n (%)	17(5)	8(4.8)	7(5.8)	1(2.3)	9(5.1)	5(6.4)	4(4.1)
N, number; RDC, renal dialysis centre, SD, standard deviation; Med, median; Q1, quartile 1; Q2, quartile 2; Mini, minimum; max, maximum							

In subdivision 1, the participant age range was 16-94 years old. The oldest (regarding dialysis duration) registered participant on dialysis who was still alive (at the time of data collection), and still on dialysis, started the dialysis in 1988. This participant was 69 years old at the time of data collection and spent 26 years of his/her life on maintenance haemodialysis.

In subdivision 2, the participant age range was 10-84 years old, and the oldest registered participant on dialysis (who was still alive at the time of data collection) had started the dialysis in 1980. This participant was 44 years old at the time of data collection and had spent 34 years of his/her entire life on maintenance haemodialysis.

Around 80% of the study population were aged less than 65 years old. Nearly half of the participants, regardless of the subdivisions, were in the 45-64 age groups (Table 8-1). The males were apparently younger ($M = 50.3$ years) compared to females ($M = 53.3$ years), however there was no statistically significant difference between males and females in

relation to age. There were six children (1.8%) in the sample population, and 335 adults (98.2% - Table 8-1 and Figure 8-1). Five out of the six identified children were from subdivision 2.

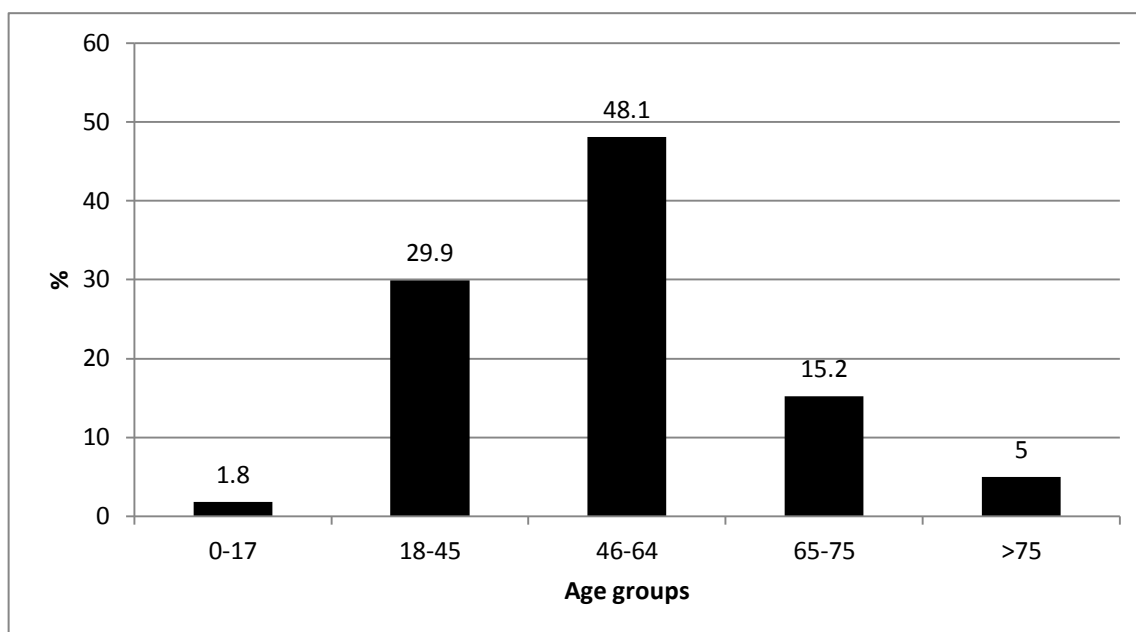


Figure 8-1 Overall age group distributions across the northern region of Oman

There were more male participants than females (54.8% vs. 45.2% - Table 8-2), with no statistically significant differences between the subdivisions ($P = 0.598$) or RDCs ($P = 0.643$).

Table 8-2 Statistical summary of the gender variable across subdivisions and RDCs

Variable	All	Subdivision 1		Subdivision 2			
	Total (n=341) n (%)	All (n=167) n (%)	RDC1 (n=123) n (%)	RDC2 (n=44) n (%)	All (n=174) n (%)	RDC3 (n=77) n (%)	RDC4 (n=97) n (%)
Males	187(54.8)	94(56.3)	69(56.1)	25(56.8)	93(53.4)	45(58.4)	48(49.5)
Females	154(45.2)	73(43.7)	54(43.9)	19(43.2)	81(46.6)	32(41.6)	49(50.5)

Across the whole sample (i.e. in the northern region of Oman) there were significantly large numbers of Omani Asians ($n = 237 = 69.5\%$), a lesser number of Omani Whites ($n = 55 = 16.1\%$), and Omani Blacks were the smallest group, represented by 49 participants

(14.4% - Table 8-3). Although the percentage of Asians was similarly high across the subdivisions and RDCs, however, it was higher in subdivision 1 as a result of higher percentages of Asians within RDC1 ($n = 88 = 71.5\%$) and RDC2 ($n = 37 = 84.1\%$). It was also described that the number of Whites was greater in subdivision 2 ($n = 44 = 25.3\%$) when compared to subdivision 1 ($n = 11 = 6.6\%$). In contrast, Blacks were relatively numerous in subdivision 1 ($n = 31 = 18.5\%$) when compared to subdivision 2 ($n = 18 = 10.3\%$ - Table 8-3). The p-value of the chi-square test was significant ($P < 0.05$) between subdivisions ($P < 0.05$) and between RDCs ($P < 0.05$), which indicates a significant statistical difference in race/ethnicity between the subdivisions and between RDCs.

Table 8-3 Statistical summary of the race/ethnicity variable across subdivisions and RDCs

Variable	All	Subdivision 1			Subdivision 2		
	Total (n=341) n (%)	All (n=167) n (%)	RDC1 (n=123) n (%)	RDC2 (n=44) n (%)	All (n=174) n (%)	RDC3 (n=77) n (%)	RDC4 (n=97) n (%)
Asians	237(69.5)	125(74.9)	88(71.5)	37(84.1)	112(64.4)	50(64.9)	62(63.9)
Whites	55(16.1)	11(6.6)	7(5.7)	4(9.1)	44(25.3)	17(22.1)	27(27.8)
Blacks	49(14.4)	31(18.5)	28(22.8)	3(6.8)	18(10.3)	10(13)	8(8.3)

Of the female participants, 103 (66.9%) were Asians, whilst 134 (71.7%) of the male participants were Asians (Table 8-4). There were more White females ($n = 26 = 16.9\%$) compared to White males ($n = 29 = 15.5\%$ - Table 8-4) and more Black females ($n = 25 = 16.2\%$) across the whole dialysis sub-population in the northern region of Oman compared to Black males ($n = 24 = 12.8\%$ - Table 8-4). Statistically, there was no evidence of statistical significant difference between gender and race/ethnicity, as the p-value was $P = 0.590$.

Table 8-4 Statistical summary of the race/ethnicity variable in relation to gender across the northern region of Oman

Variable	Gender		
	Total (n = 341) n (%)	Female (n = 154) n (%)	Male (n = 187) n (%)
Ethnicity			
Asians	237(69.5)	103(66.9)	134(71.7)
Whites	55(16.1)	26(16.9)	29(15.5)
Blacks	49(14.4)	25(16.2)	24(12.8)

The majority of the participants were married ($n = 214 = 62.8\%$), 54 (15.8%) were single (i.e. never married), 51 were widowed (15%) and 22 were divorced (6.4% - Table 8-5). The divorced sub-set were asked if their divorce happened because of their chronic kidney failure and their prolonged treatment (dialysis), as a result eight out of the 22 divorced participants reported that their divorce was an outcome of their chronic treatment (Table 8-5).

Table 8-5 Statistical summary of the marital status variable across all subdivisions and RDCs

Variable	All	Subdivision 1			Subdivision 2		
	Total (n=341) n (%)	All (n=167) n (%)	RDC1 (n=123) n (%)	RDC2 (n=44) n (%)	All (n=174) n (%)	RDC3 (n=77) n (%)	RDC4 (n=97) n (%)
Married	214(62.8)	107(64)	75(61)	32(72.7)	107(61.5)	47(61)	60(61.9)
Widowed	51(15)	25(15)	20(16.3)	5(11.4)	26(14.9)	11(14.3)	15(15.5)
Single	54(15.8)	23(13.8)	19(15.4)	4(9.1)	31(17.8)	13(16.9)	18(18.5)
Divorced	22(6.4)	12(7.2)	9(7.3)	3(6.8)	10(5.8)	6(7.8)	4(4.1)
Because of KF	8(38.1)	2(9.5)	2(9.5)	0	6(28.6)	5(23.8)	1(4.8)

KF, Kidney Failure

It was described that the divorce figure appeared higher in subdivision 1 ($n = 12 = 7.2\%$) compared to subdivision 2 ($n = 10 = 5.8\%$ - Table 8-5). The p-value was $P > 0.05$, showing no statistical significant difference in divorce rates between subdivisions ($P = 0.49$) and between RDCs ($P = 0.48$). The divorce figure was higher among female dialysis participants ($n = 13 = 8.4\%$) compared to male participants ($n = 9 = 4.8\%$). Statistically, there was evidence of significant difference between gender and marital status across the whole sample ($P < 0.05$ - Table 8-6).

Table 8-6 Statistical summary of the marital status variable in relation to the gender variable across the northern region of Oman

Variable	Gender		
	Total (n = 341) n(%)	Female (n = 154) n(%)	Male (n = 187) n(%)
Married	214 (62.8)	85(55.3)	129(69)
Widowed	51(15)	37(24)	14(7.5)
Single	54(15.8)	19(12.3)	35(18.7)
Divorced	22(6.4)	13 (8.4)	9(4.8)

The vast majority of participants were unemployed ($n = 292 = 85.6\%$ - Table 8-7), with only 62 (21.2 %) participants said that they were fired from their job because of their sickness. The employment status was almost the same across the subdivisions or RDCs. The p-value was $P > 0.05$, showing no statistical significant difference between subdivisions ($P = 0.537$) or between RDCs ($P = 0.942$ - Table 8-7). The reported education level of the surveyed participants was as follows: illiterate ($n = 164 = 48\%$), read and write ($n = 51 = 15\%$), primary education ($n = 47 = 13.8\%$), secondary school ($n = 58 = 17\%$), college degree ($n = 18 = 5.3\%$) and post-college education ($n = 3 = 0.9\%$). It was described that nearly half of the surveyed participants were illiterate (Table 8-7).

Table 8-7 Statistical summary of the educational level and employment status variables across the northern region of Oman

Variable	All	Subdivision 1			Subdivision 2		
	Total (n=341) n (%)	All (n=167) n (%)	RDC1 (n=123) n (%)	RDC2 (n=44) n (%)	All (n=174) n (%)	RDC3 (n=77) n (%)	RDC4 (n=97) n (%)
Employed	49(14.4)	22(13.2)	16(13)	6(13.6)	27(15.5)	12(15.6)	15(15.5)
Unemployed	292(85.6)	145(86.8)	107(87)	38(86.4)	147(84.5)	65(84.4)	82(84.5)
Because of KF	62(21.2)	28(9.6)	15(5.1)	13(4.5)	34(11.6)	18(6.2)	16(5.4)
Illiterate	164(48.1)	72(43)	55(44.7)	17(38.6)	92(52.9)	32(41.6)	60(61.9)
Read & write	51(15)	31(18.6)	21(17.1)	10(22.7)	20(11.5)	14(18.2)	6(6.2)
Primary	47(13.7)	28(16.8)	18(14.6)	10(22.7)	19(10.9)	9(11.7)	10(10.3)
Secondary	58(17)	28(16.8)	24(19.5)	4(9.1)	30(17.2)	15(19.5)	15(15.5)
College	18(5.3)	7(4.2)	5(4.1)	2(4.5)	11(6.3)	6(7.8)	5(5.1)
Post-college	3(0.9)	1(0.6)	0(0)	1(2.4)	2(1.2)	1(1.2)	1(1)

The literacy status in general was similar across the subdivisions and RDCs. The p-value also showed no evidence of statistical significant difference between subdivisions ($P = 0.174$) or RDCs ($P = 0.084$). However there were more illiterate females compared to males, with 103 (66.9%) illiterate females compared to 61 (32.6%) males across the whole sample of the dialysis sub-population of the northern region of Oman Table 8-8). The post-college cohort was all males, with no females in this category (Table 8-8). Statistically, there was a significant difference between the variables of education and gender ($P < 0.05$). The statistics showed that the 18-44 age groups were a more educated population, while the over 75 age group was less educated (Table 8-8). The p-value was ($P < 0.05$), showing a significant difference between education and age groups.

Table 8-8 Statistical summary of the education variable in relation to gender and age group variables across the northern region of Oman

Variable	Gender			Age group				
	Total n(%)	Female n(%)	Male n(%)	0-17 n(%)	18-45 n (%)	46-64 n (%)	65-75 n (%)	>75 n (%)
Illiterate	164(48.1)	103(66.9)	61(32.6)	1(16.7)	13(12.7)	99(60.4)	38(73.1)	13(76.5)
Read & write	51(15)	15(9.7)	36(19.3)	1(16.7)	4(3.9)	31(18.9)	11(21.2)	4(23.5)
Primary	47(13.7)	14(9.1)	33(17.6)	3(49.9)	21(20.6)	22(13.4)	1(1.9)	0
Secondary	58(17)	19(12.4)	39(20.9)	1(16.7)	45(44.1)	10(6.1)	2(3.8)	0
College	18(5.3)	3(1.9)	15(8)	0	17(16.7)	1(.6)	0	0
Post-college	3(0.9)	0	3(1.6)	0	2(2)	1(0.6)	0	0

No participants were living alone, but all were living in families, either in rural ($n = 239 = 70.1\%$) or urban areas ($n = 99 = 29\%$ - Table 8-9). It was observed that the number of participants living in rural areas was higher compared to those in urban areas, across all RDCs (Table 8-9) except RDC2 ($n = 16 = 36.4\%$), where it was the opposite (i.e. more lived in urban areas). However, most of the participants surveyed were not sufficiently certain as to whether the area they lived in was rural or urban. Statistically, there was a significant difference in the variable of residential status between subdivisions ($P < 0.05$) and between RDCs ($P < 0.05$).

Table 8-9 Statistical summary of residential status across subdivisions and RDCs

Variable	All	Subdivision 1			Subdivision 2		
	Total (n=341) n (%)	All (n=167) n (%)	RDC1 (n=123) n (%)	RDC2 (n=44) n (%)	All (n=174) n (%)	RDC3 (n=77) n (%)	RDC4 (n=97) n (%)
Urban	99(29)	45(26.9)	17(13.8)	28(63.6)	54(31)	27(35.1)	27(27.8)
Rural	239(70.1)	120(71.9)	104(84.6)	16(36.4)	119(68.4)	50(64.9)	69(71.1)
Mixed	3(0.9)	2(1.2)	2(1.6)	0	1(0.6)	0	1(1.1)

8.1.2 Participant distribution across districts

The four RDCs of this study served the sub-population on maintenance dialysis from 12 districts (Figure 8-2). The largest number of participants came from District 1 ($n = 62 = 18.2\%$), followed by those from District 6 ($n = 58 = 17\%$), and those from District 11 ($n = 55 = 16\%$). The smallest number of participants came from District 8 and District 9 ($n = 8 = 2.4\%$) and District 7 ($n = 5 = 1.5\%$).

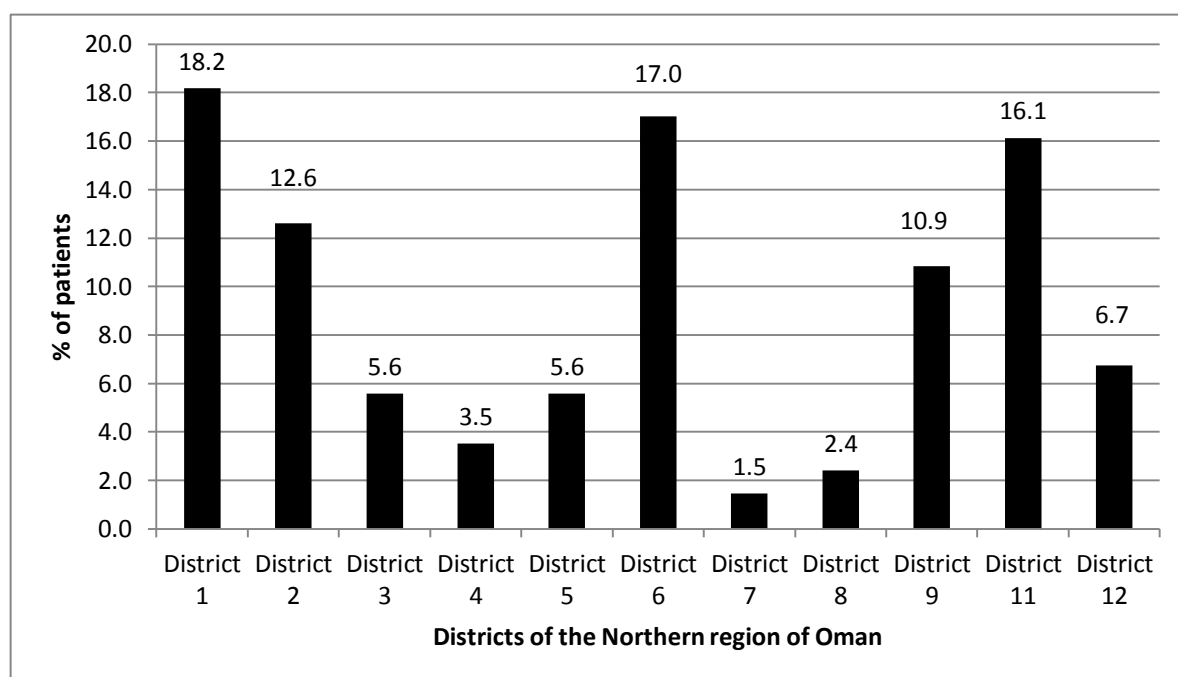


Figure 8-2 Dialysis sub-population across the northern region of Oman's districts

It was noticed that the figures for males were slightly higher than for females across the districts (e.g. in District 6 - males were 9.4% vs. 7.6% females), except in District 1 (males, 8.8% vs. females, 9.4%) and District 3 (males, 2.3% vs. females 3.3%): where the figures for females appeared slightly higher than for males (Figure 8-3). However, the p-value of the chi-square test showed no evidence of statistical significant difference in gender across the districts ($P = 0.682$).

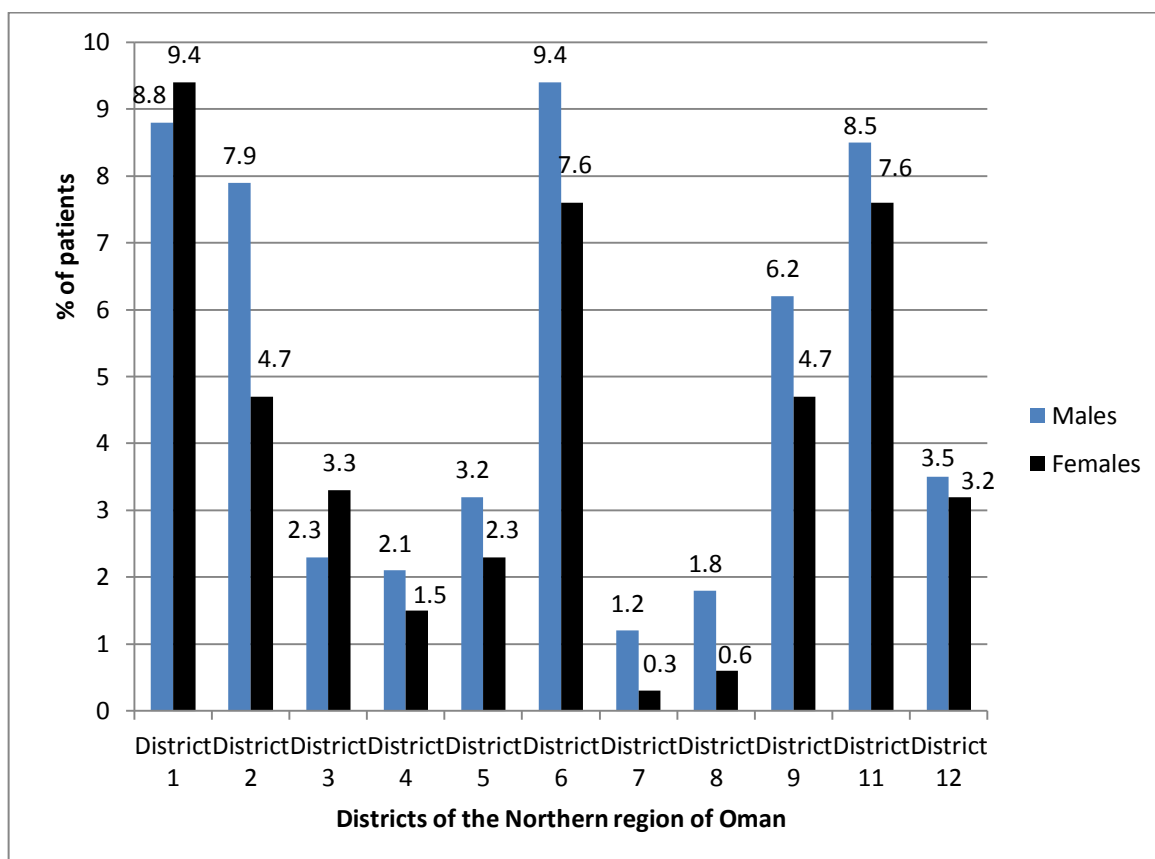


Figure 8-3 Treated dialysis sub-population across districts of the north in relation to gender

The distribution of the age groups was similar across all districts, and the chi-square test presented no significant difference in distribution ($P = 0.859$). The only difference was that paediatric participants were coming from only four districts (i.e. Districts 1, 2, 5, and 6) out of the 12 districts of the northern region of Oman. Furthermore, when the education status, compared across the districts, was almost the same, and the chi-square tests showed no evidence of significant difference ($P = 0.924$).

8.1.3 Participant perception on the risk factors

All the surveyed participants were asked to identify the risk factors apparent to them at the phase preceding their diagnosis with kidney failure, or at the time of their diagnosis with kidney failure. Most of the listed risk factors had no clinical evidence in the patients' profiles when compared except for hypertension or diabetes which were well evidenced in most of the patient medical profiles. The participant had to select any or all of the 21 risk factors listed in the survey that was applicable to them. Hypertension was the most common risk factor, reported frequently by the participants (14.2%). Second was obesity (11.5%) and third was diabetes (8.6%). Cultural factors came fourth (8.4%), low socio-

economic status fifth (6.9%), and limited access sixth (6.5%) and few participants chose the remaining risk factors on the list (Figure 8-4).

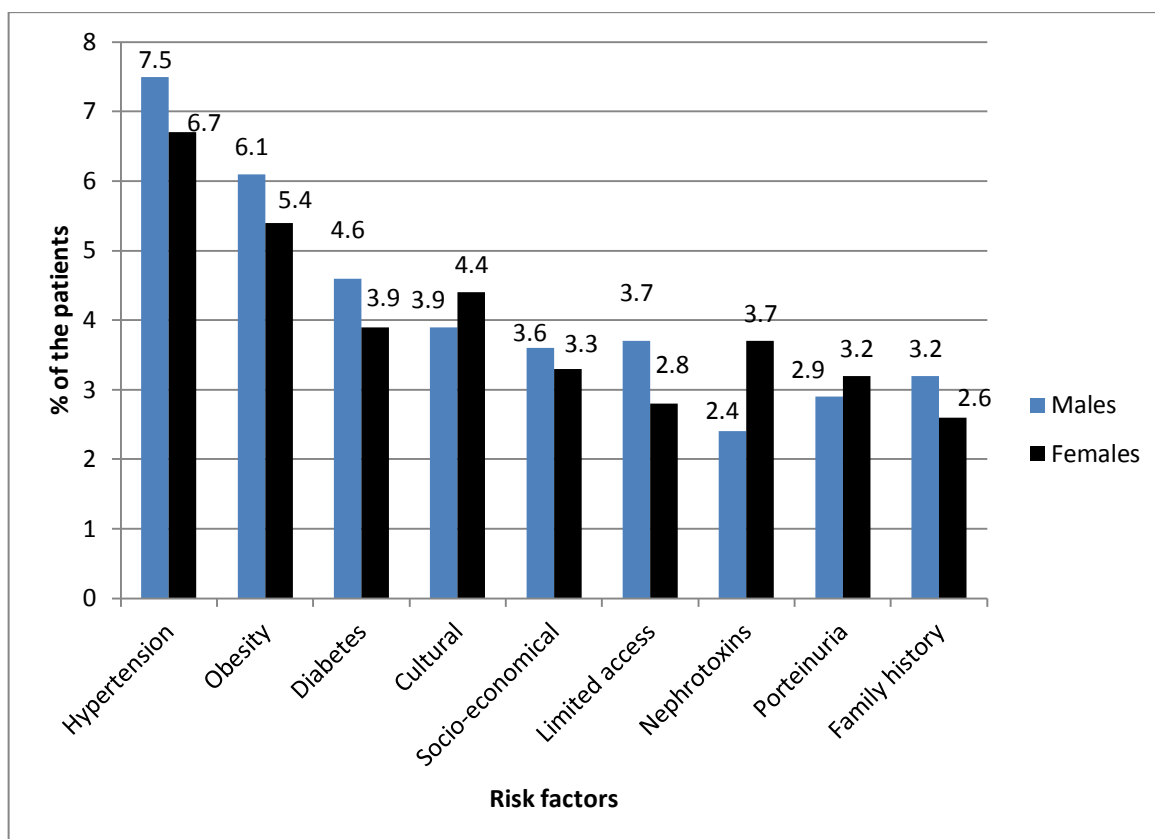


Figure 8-4 participants perceived top nine risk factors across the northern region of Oman compared to gender

It was noticed that when compared to males, females had slightly higher percentages for five risk factors: first was nephrotoxins (males, 2.4 % vs. females, 3.7%), second was proteinuria (males, 2.9% vs. females, 3.2 % - note: the missing responses for this variable were more than 5% which may give this statistics less reliability), third was dyslipidaemia (males, 2.3 % vs. females, 2.4%), fourth was late diagnosis (males, 2.1 % vs. females 2.4%), and fifth was anaemia (males, 0.9 % vs. females,1.1% - Figure 8-4). Another result was the higher percentages of hypertension in District 6 (18%), District 1 (15.2%) and District 2 (10.6%), and the low percentages in District 7 (1.4%), District 8 (1.4%), and District 10 (0.5%). Also the highest percentage of obesity was described in District 1 (24.4%), and the lowest in District 7 (0.6%). Comparing the risk factors across subdivisions revealed that subdivision 1 participants appeared to have more hypertension (55.8%) compared to subdivision 2 (44.2%). However, subdivision 2 appeared to have more obesity (63.6%) and diabetes (52.7%) compared to subdivision 1 which had obesity at 36.4% and diabetes at 47.3%.

8.1.4 Participant primary diseases and causes

Overall, the top four primary diseases reported by participants were hypertension ($n = 161 = 47.5\%$), diabetes ($n = 77 = 22.7\%$), diabetes and hypertension combined ($n = 55 = 16.2\%$), and finally other medical problems such as polycystic kidneys, heart problems, hyperthyroidism and anaemia ($n = 88 = 26\%$ - Table 8-10). It is described that more than half of the surveyed participants reported diabetes, hypertension or combined as the primary disease. Also, these primary diseases were counter checked by the patients' medical records.

Table 8-10 Statistical summary of the primary diseases variable across all subdivisions and RDCs

Variable	All	Subdivision 1			Subdivision 2		
	Total (n=341) n (%)	All (n=167) n (%)	RDC1 (n=123) n (%)	RDC2 (n=44) n (%)	All (n=174) n (%)	RDC3 (n=77) n (%)	RDC4 (n=97) n (%)
DM	77(22.7)	23(13.9)	8(4.8)	15(9)	54(31.2)	22(12.7)	32(18.5)
HTN	161(47.5)	81(48.8)	60(36.1)	21(12.7)	80(46.2)	40(23.1)	40(23.1)
DM & HTN	55(16.2)	39(23.5)	39(23.5)	0	16(9.2)	2(1.2)	14(8.1)
Genetics	10(2.9)	4(2.4)	3(1.8)	1(0.6)	6(3.5)	2(1.2)	4(2.3)
SLE	20(5.9)	13(7.8)	11(6.6)	2(1.2)	7(4)	4(2.3)	3(1.7)
Urological	9(2.7)	7(4.2)	6(3.6)	1(0.6)	2(1.2)	0	2(1.2)
Others	88(26)	42(25.3)	28(16.9)	14(8.4)	46(26.6)	17(9.8)	29(16.8)

DM & HTN, diabetes and hypertension; SLE, systemic lupus erythematosus

There was no evidence of significant statistical difference in primary diseases across the subdivisions and RDCs, except with diabetes ($P < 0.05$) or diabetes and hypertension combined ($P < 0.05$ - Figure 8-5), both of which had evidence of significant statistical difference.

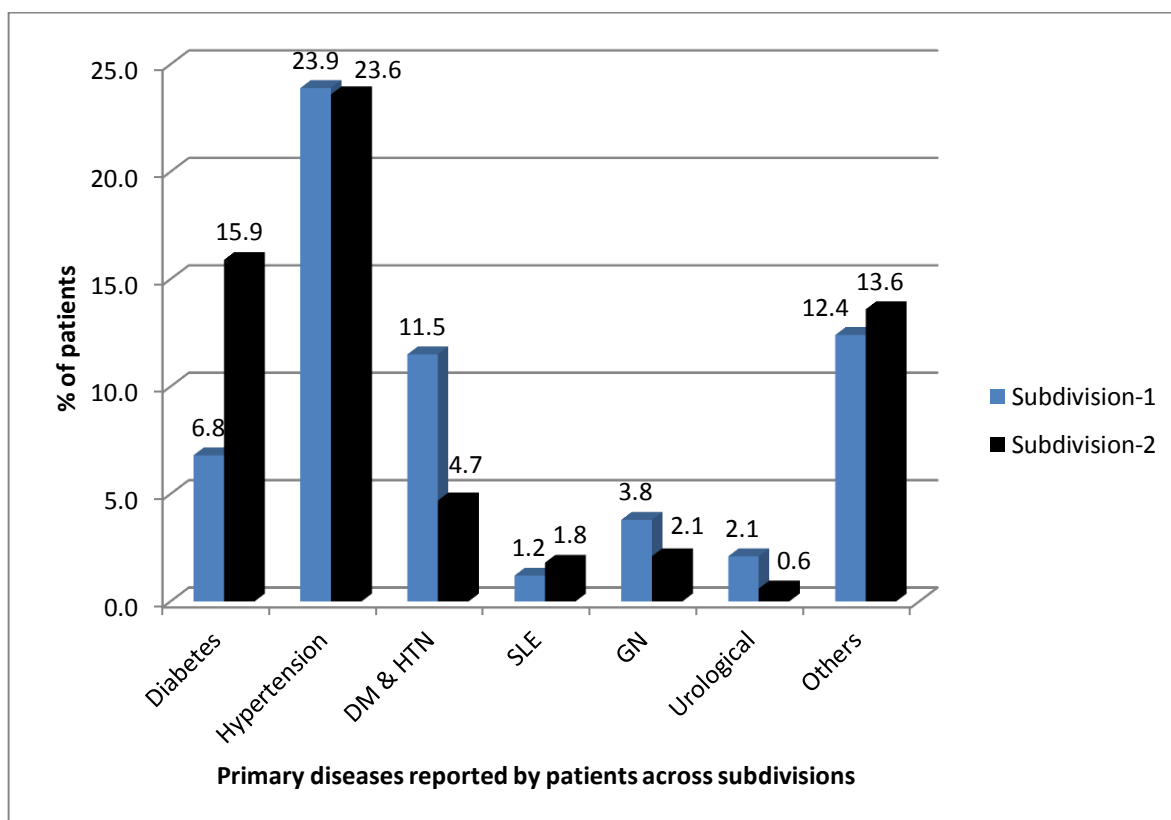


Figure 8-5 Primary diseases distribution across subdivisions

It was described that the male figures for primary diseases are higher than those for females, except in RDC4, where females reported more diabetes compared to males (males 43.8% vs. females 56.3%). Males have also reported less systemic lupus erythematosus (SLE) and glomerulonephritis (GN) compared to females. These results follow the normal trends reported by the literature, as SLE is more prevalent in females than in males, which may be due to differences in sex hormones and gonadotropin-releasing hormone (Wasef, 2004 - Table 8-11).

Table 8-11 Statistical summary of the primary diseases variable in relation to the gender variable across the whole sample in the north of Oman

Variable	Gender		
	Total n(%)	Female n(%)	Male n(%)
DM	77(22.6)	32(41.6)	45(58.4)
HTN	161(47.2)	76(47.2)	85(52.8)
*DM & HTN	55(16.1)	27(49.1)	28(50.9)
SLE	10(2.9)	5(50)	5(50)
*GN	20(5.9)	10(50)	10(50)
Urological	9(2.6)	2(22.2)	7(77.8)
Others	88(25.8)	41(46.6)	47(53.4)

*DM & HTN, diabetes and hypertension; GN, glomerulonephritis

Participants were also asked to express their thoughts on what might be the cause of their kidney failure. Many participants perceived it might be hypertension ($n = 112 = 32.8\%$), diabetes ($n = 67 = 19.6\%$), diabetes and hypertension combined ($n = 44 = 12.9\%$), or other mixed causes (34.7%), which included nephrotoxins (e.g. NSAIDs, 1.2%) and medical errors (e.g. medication errors and misdiagnosis, 0.6% - Figure 8-6). It was also observed that while reporting their diabetes, hypertension or other causes, participants frequently combined other problems with their primary cause. Examples of this were diabetes and non-compliance, or hypertension and ignorance (3.5% of the participants reported non-compliance and ignorance, mainly because of denial of the problem or lack of trust in the success of the treatment).

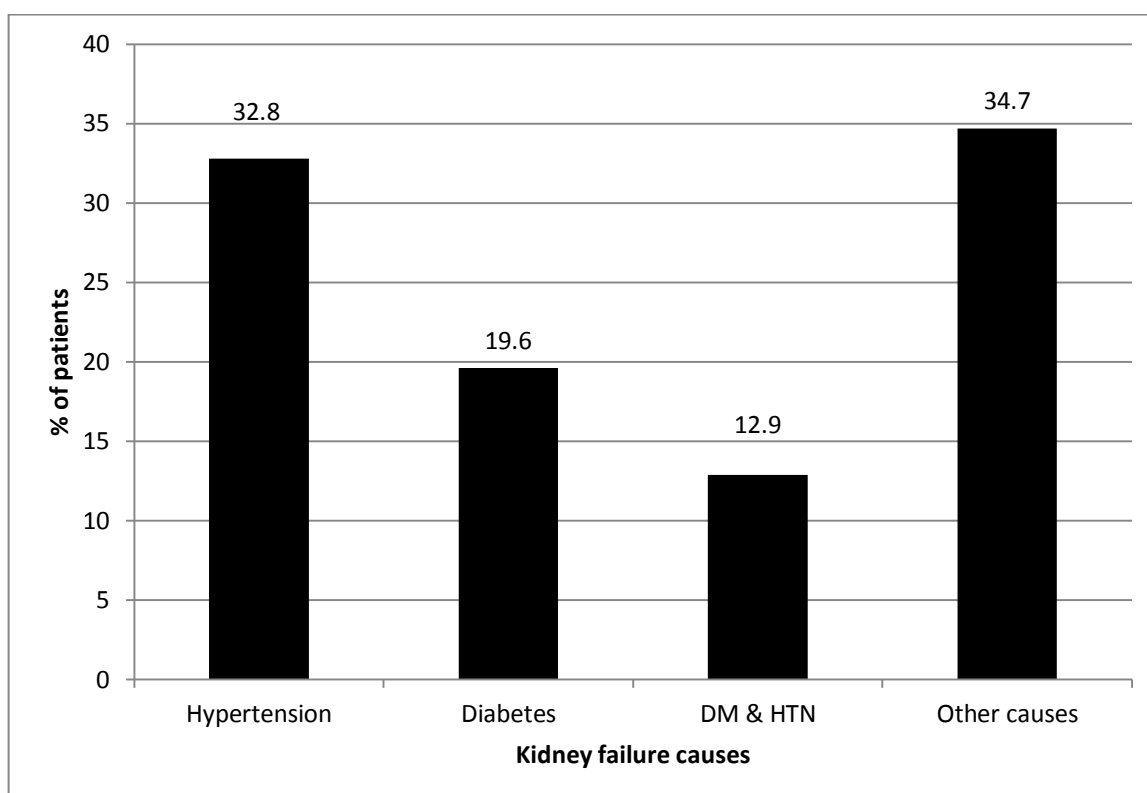


Figure 8-6 Participant perceptions on their kidney failure causes

8.1.5 Participant co-morbidities profile

The most common co-morbidities reported by participants (and counter checked by their medical records) were, firstly, diabetes and hypertension combined ($n = 156 = 45.7\%$), followed by hypertension only ($n = 136 = 39.9\%$), then other mixed co-morbidities ($n = 90 = 26.4\%$) such as anaemia, hyperparathyroidism, asthma and neurogenic bladder, then cardiovascular disease ($n = 83 = 24.3\%$), diabetes only ($n = 9 = 2.6\%$), and finally SLE ($n = 7 = 2.1\%$ - Table 8-12).

Table 8-12 Statistical summary of the co-morbidities variable across all subdivisions and RDCs

Variable	All	Subdivision 1			Subdivision 2		
	Total (n=341) n (%)	All (n=167) n (%)	RDC1 (n=123) n (%)	RDC2 (n=44) n (%)	All (n=174) n (%)	RDC3 (n=77) n (%)	RDC4 (n=97) n (%)
DM & HTN*	156(45.7)	69(20.2)	51(15)	18(5.3)	87(25.5)	30(8.8)	57(16.7)
HTN	136(39.9)	72(21.1)	56(16.4)	16(4.7)	64(18.8)	34(10)	30(8.8)
Others	90(26.4)	45(13.2)	32(9.4)	13(3.8)	45(13.2)	21(6.2)	24(7)
CVD*	83(24.3)	27(7.9)	17(5)	10(2.9)	56(16.4)	24(7)	32(9.4)
DM	9(2.6)	6(1.8)	2(0.6)	4(1.2)	3(0.9)	2(0.6)	1(0.3)
SLE	7(2.1)	5(1.5)	3(0.9)	2(0.6)	2(0.6)	1(0.3)	1(0.3)

*DM & HTN, diabetes and hypertension; CVD, cardiovascular disease; SLE, systemic lupus erythematosus

Across the northern region of Oman, males appeared to have more of all reported co-morbidities compared to females, except for SLE. For SLE, females had higher percentages (85.7%) compared to males (14.3% - Table 8-13).

Table 8-13 Statistical summary of the co-morbidities variable in relation to the gender variable across the northern region of Oman

Variable	Gender		
	Total n(%)	Female n(%)	Male n(%)
DM & HTN	156(45.7)	76(48.7)	80(51.3)
HTN	136(39.9)	61(44.9)	75(55.1)
Others	90(26.4)	46(51.1)	44(48.9)
CVD	83(24.3)	38(45.8)	45(54.2)
DM	9(2.6)	3(33.3)	6(66.7)
SLE	7(2.1)	6(85.7)	1(14.3)

DM & HTN, diabetes and hypertension; CVD, cardiovascular disease; SLE, systemic lupus erythematosus

8.1.6 Participant haemodialysis characteristics

○ *Diagnostic investigations*

Participants were asked to identify how their kidney failure was diagnosed, by selecting one or more of the following diagnostic tests: blood, urine, imaging tests, eGFR, kidney biopsy, nephrologist's opinion or perhaps other tests performed.

All participants (341) underwent blood tests and received nephrologists' opinions to confirm their kidney failure diagnosis. Imaging tests were reported by 95.3% ($n = 325$ participants) and urine tests by 90.9% ($n = 310$ participants). Kidney biopsies were reported by 8.2% ($n = 28$ participants) and eGFR was reported by 0.3% ($n = one$ participant). Other investigations such as MRI (magnetic resonance imaging) were reported by only 0.3% ($n = one$ participant - Figure 8-7). There was no statistical evidence of difference across subdivisions or across RDCs, as the p-value was for both at $P > 0.05$.

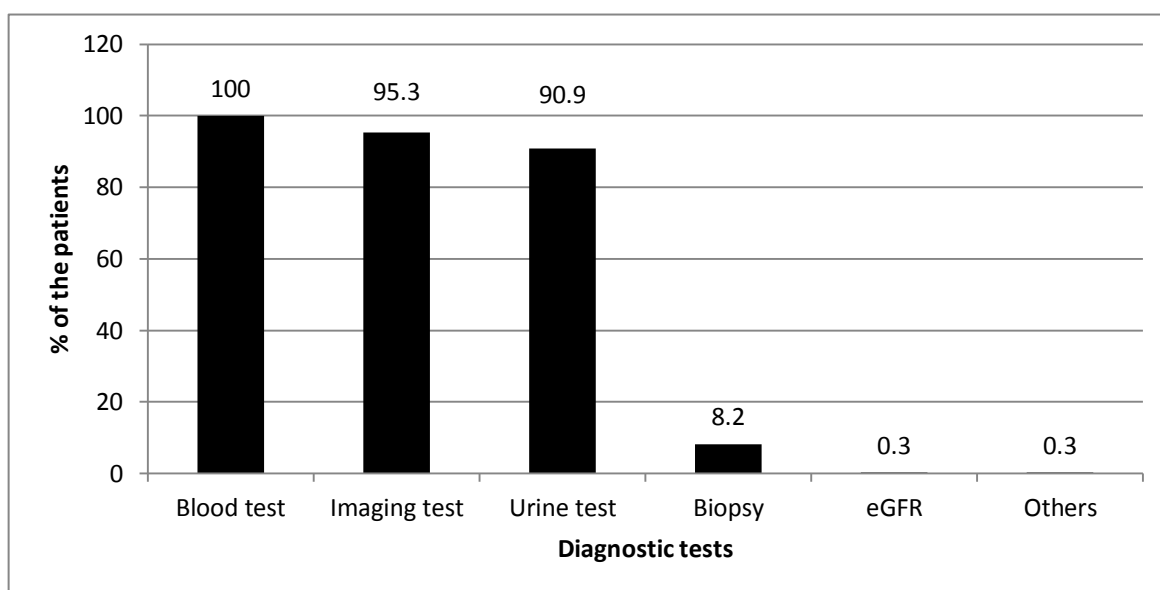


Figure 8-7 Kidney failure diagnostic tests reported by participants across the northern region of Oman

○ *Vascular access for haemodialysis*

The most common vascular access was the permanent arteriovenous fistula (AVF - $n = 272 = 79.8%$ - Table 8-14). In comparing types of vascular access across the subdivisions, it was noticed that subdivision 1 participants reported only three types of vascular access, arteriovenous fistula, arteriovenous graft and P-cath, while subdivision 2 participants

reported more types of vascular access, including femoral venous catheter and jugular venous catheter (Table 8-14). The p-value was $P > 0.05$, which indicates no significant statistical difference in types of vascular access across subdivisions ($P = 0.130$) and RDCs ($P = 0.174$).

Table 8-14 Statistical summary of the vascular accesses variable across all subdivisions and RDCs

Variable	All	Subdivision 1			Subdivision 2		
	Total (n=341) n (%)	All (n=167) n (%)	RDC1 (n=123) n (%)	RDC2 (n=44) n (%)	All (n=174) n (%)	RDC3 (n=77) n (%)	RDC4 (n=97) n (%)
AVF	272(79.8)	140(41.1)	103(30.2)	37(10.9)	132(38.7)	64(18.8)	68(19.9)
AVG	23(6.7)	11(3.2)	7(2.1)	4(1.2)	12(3.5)	4(1.2)	8(2.3)
P-cath	41(12)	16(4.7)	13(3.8)	3(0.9)	25(7.3)	7(2.1)	18(5.3)
FVC	1(0.3)	0	0	0	1(0.3)	1(0.3)	0
JVC	8(1.2)	0	0	0	4(1.2)	1(0.3)	3(0.9)

AVF, arteriovenous fistula; AVG, arteriovenous graft; P-Cath, permicath; FVC, femoral venous catheter; JVC, jugular venous catheter

○ **Haemodialysis dose, duration and timing**

All the participants ($n = 341$) surveyed were on haemodialysis modality. Most of this study population started the dialysis either immediately or within three months after their definite diagnosis of kidney failure ($n = 267 = 78.3\%$). However, six patients from RDC4 were on peritoneal dialysis, so were excluded from the study. RDC4 was the only RDC that had patients on peritoneal dialysis modality at the time of data collection. At the time of data collection nearly half of the participants had survived on dialysis for an average of five years (48.4% - Table 8-15).

Table 8-15 Duration of survival on dialysis in years across the whole sample at the time of data collection

Years on dialysis	N	%
0-1	51	15
1-5	165	48.4
5-10	87	25.5
10-20	34	10
20-30	3	0.9
>30	1	0.3
Total	341	100

Nearly two thirds (62.5%) of this study population were on three dialysis sessions a week, or a minimum of nine dialysis hours per week. Two sessions of dialysis per week was the rate for 36.1% of participants, which is a minimum of five hours of dialysis per week. Only 1.5% was following a non-fixed schedule (i.e. sometimes two sessions a week and other times three sessions a week - or one session per week in a few cases). Less than half of the participants (41.9%) were attending their dialysis sessions in the afternoon or evening. Some of the participants were attending dialysis sessions at differing times: sometimes in the morning, sometimes in the afternoon or evening. The remaining participants (22.9%) were attending morning sessions.

The majority of participants ($n = 296 = 86.8\%$) were comfortable with their dialysis timing; however, 45 participants (13.2%) said they did not like the timetable of their weekly dialysis. There were some variations between RDCs regarding frequency and timing of haemodialysis, and to illustrate this further each RDC is described separately in appendix G (see p.272).

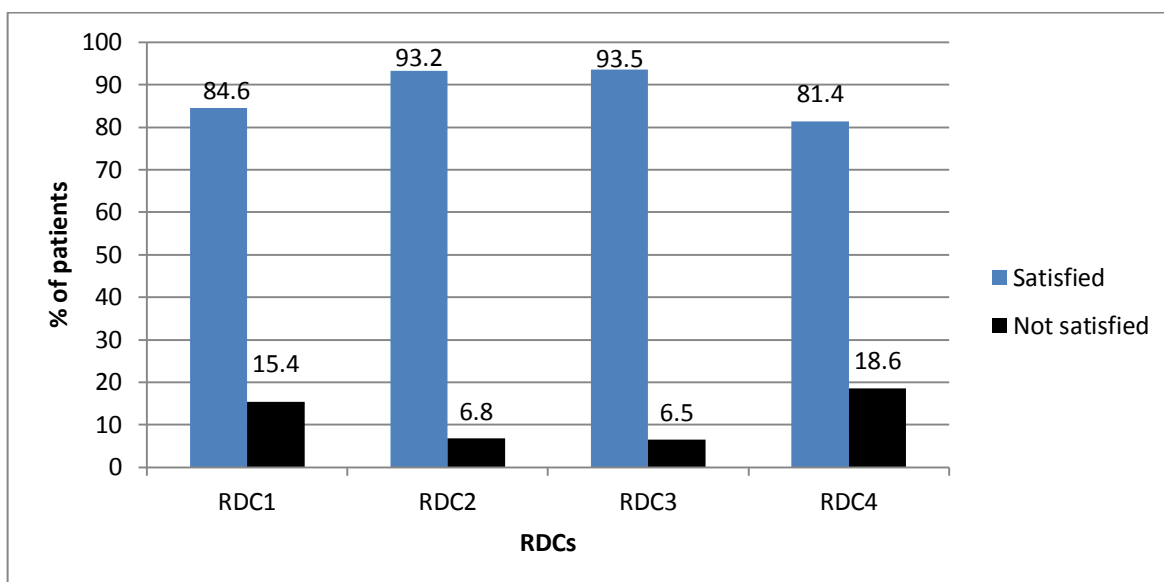


Figure 8-8 Participant satisfaction regarding haemodialysis frequency and timing across the four RDCs

8.1.7 Participant perceptions on the impact of dialysis treatment on their lives

The overall findings of this item showed that most participants ($n = 288 = 84.5\%$) felt that dialysis treatment caused no interference to their lives, and the difference across subdivisions ($P = 0.227$), and between RDCs ($P = 0.007$) was not statistically significant. Many participants did not feel that they caused a burden on their family or the community ($n = 283 = 83\%$) with no statistically significant difference between subdivisions ($P = 0.907$) or RDCs ($P = 0.009$ - Table 8-16). The majority felt psychologically stable, with few worries or frustrations ($n = 291 = 85.3\%$) with no statistically significant difference between subdivisions ($P = 0.446$), but with statistically significant difference between RDCs ($P = 0.003$). Most of the participants ($n = 286 = 83.9\%$) had no financial difficulties secondary to their commitments to the dialysis treatment with statistically significant difference between subdivisions ($P = 0.003$), and between RDCs ($P < 0.05$).

Table 8-16 Statistical summary of the reported impact of dialysis treatment on participant lives across subdivisions and RDCs

Variable	All		Subdivision 1				Subdivision 2							
	Total (n=341)		All (n=167)		RDC1 (n=123)		RDC2 (n=44)		All (n=174)		RDC3 (n=77)		RDC4 (n=97)	
54. My kidney disease and its treatment interfere too much with my life.	Yes	15.5 %	Yes	8.8 %	Yes	5.3 %	Yes	3.5 %	Yes	6.8 %	Yes	1.2 %	Yes	5.6 %
	No	84.5 %	No	40.2 %	No	30.8 %	No	9.4 %	No	44.3 %	No	21.4 %	No	22.9 %
55. I feel like a burden on my family and the community.	Yes	17 %	Yes	8.2 %	Yes	5.0 %	Yes	3.2 %	Yes	8.8 %	Yes	1.8 %	Yes	7.0 %
	No	83 %	No	41.0 %	No	31.3 %	No	9.7 %	No	42.2 %	No	20.8 %	No	21.4 %
56. I feel frustrated and worried when dealing with my disease.	Yes	14.7 %	Yes	6.4 %	Yes	2.9 %	Yes	3.5 %	Yes	8.2 %	Yes	2.3 %	Yes	5.9 %
	No	85.3 %	No	42.5 %	No	33.1 %	No	9.4 %	No	42.8 %	No	20.2 %	No	22.6 %
57. I do not have sufficient income because of my dialysis treatment.	Yes	16.1 %	Yes	5.0 %	Yes	1.8 %	Yes	3.2 %	Yes	11.1 %	Yes	2.3 %	Yes	8.8 %
	No	83.9 %	No	44.0 %	No	34.3 %	No	9.7 %	No	39.9 %	No	20.2 %	No	19.6 %

8.1.8 Participant death figures in 2014 and in 2015

The overall death figures in the four RDCs combined was 42 dialysis patients in 2014, with 13 females (31%) and 29 males (69%). In 2015, 57 dialysis patients died: 29 females (50.9%), and 28 males (49.1%). Therefore the total death figure for both years combined was 99 deaths, however for 22 (22.2%) of these – all from RDC4 in 2014 - the cause was not reported. The causes of death overall, for 2014 and 2015, were cardiovascular (CVD - $n = 41 = 41.5\%$), infection ($n = 10 = 10.2\%$), unknown or unreported causes ($n = 5 = 5.2\%$), respiratory ($n = 4 = 4\%$), and other causes such as: cancer ($n = 1 = 1.2\%$), cerebrovascular (CVA - $n = 1 = 1.2\%$), gastrointestinal bleeding ($n = 1 = 1.2\%$), and poly-

trauma ($n = 1 = 1.2\%$ - Figure 8-9). The average survival rate for those on dialysis from their start of dialysis treatment and until death across three RDCs (this was not possible to calculate for RDC2 – see next paragraph for details) was 6.9 years per survivor. As there is some missing data in this domain and there were some variations between the individual RDCs, the death profiles for individual RDCs are illustrated next.

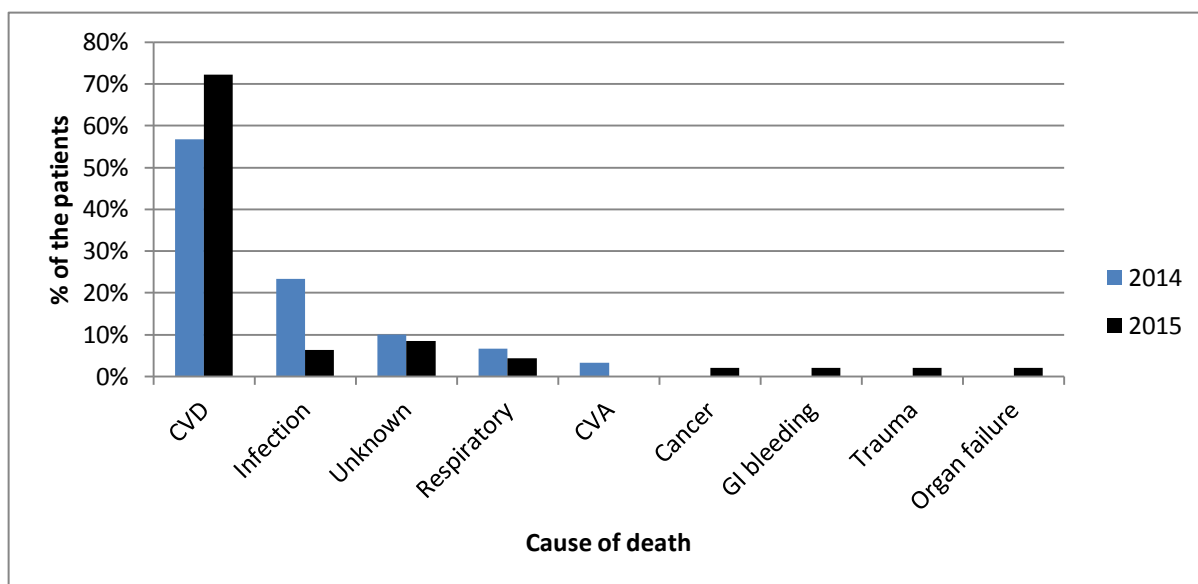


Figure 8-9 Comparison of causes of death between the years 2014 and 2015 across the whole sample the northern region of Oman

RDC1 had 15 deaths in 2014, with 11 (73.3%) males and 4 (26.7%) females. The most common cause was cardiovascular diseases ($n = 9 = 60\%$), followed by infection ($n = 4 = 26.6\%$), respiratory arrest ($n = 1 = 6.7\%$), and cerebrovascular accident ($n = 1 = 6.7\%$ - Figure 8-9). In 2015, there were 11 deaths, five (45.5%) males to six (54.5%) females. The causes of death reported were cardiovascular ($n = 8 = 72.7\%$), respiratory ($n = 1 = 9.1\%$), and cancer ($n = 1 = 9.1\%$). The range of survival on dialysis treatment for the 11 participants who had been surveyed and died during data collection was 3-19 years. The average survival rate on dialysis for the same cohort was 7.3 years of dialysis per patient.

In RDC2 nine participants died in 2014 (Figure 8-10), six (66.6%) males and three (33.4%) females. The causes of death as reported were cardiovascular ($n = 3 = 33.3\%$), unknown or unreported causes ($n = 3 = 33.3\%$), infection ($n = 2 = 22.3\%$), and respiratory ($n = 1 = 11.1\%$). In 2015, there were 14 deaths (Figure 8-10) during the year, eight (57.2%) males to six (42.8%) females. The reported causes of death were cardiovascular ($n = 8 = 57.2\%$), infection ($n = 2 = 14.3\%$), unknown or unreported ($n = 2 = 14.3\%$), respiratory ($n = 1 =$

7.1%), and gastrointestinal bleeding ($n = 1 = 7.1\%$). The range of survival on dialysis was not possible to calculate because only one participant found his/her data, and it seemed the others were not captured by this study because they started after the interviews (i.e. they were not included in the sample) and died during the year 2015, which was confirmed later by the RDC's staff.

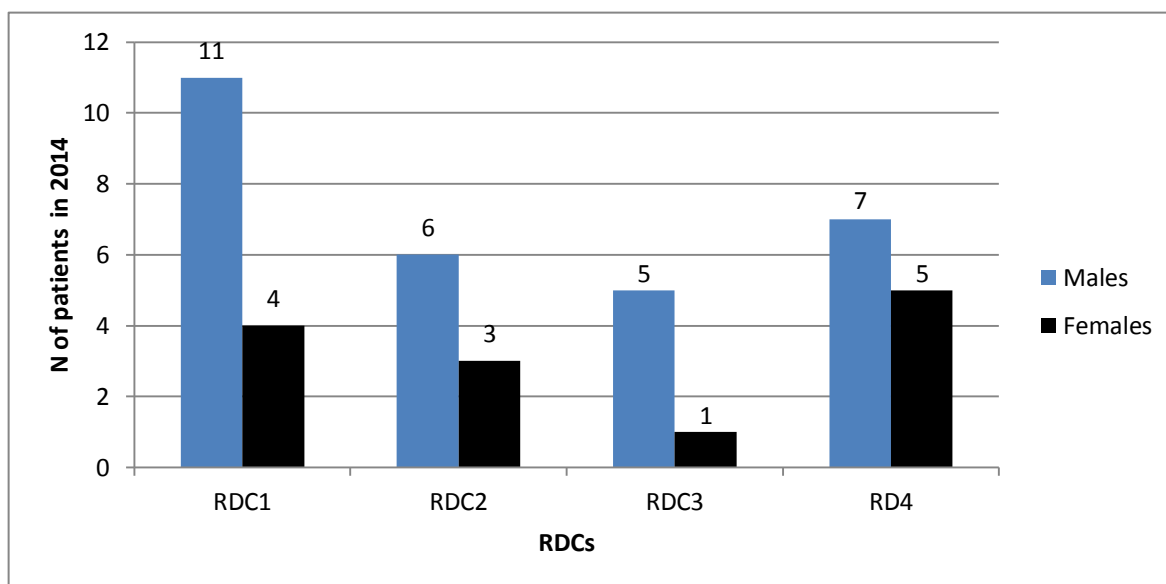


Figure 8-10 Death figures across RDCs in 2014

RDC3 reported the deaths of six participants in 2014 (Figure 5.17), with five (83.3%) males and one (16.7%) female. The reported causes of death were cardiovascular for five participants (83.3%), and infection for the other (16.7%). In 2015, ten participant deaths were reported, seven (70%) males to three (30%) females (Figure 8-11). The reported causes of death were cardiovascular ($n = 8 = 80\%$), infection ($n = 1 = 10\%$), and poly-trauma ($n = 1 = 10\%$). The range of dialysis survival for the ten participants who had been surveyed and who died during data collection was 2-14 years. The average survival rate was 5.75 years on dialysis per patient.

RDC4 had 12 deaths in 2014, seven (58.3%) males and five (41.7%) females (Figure 8-10). The causes were not reported for 2014. In 2015, the reported death rate was 22 patients, eight (36.4%) males to 14 (63.6%) females (Figure 8-11). This RDC only reported the causes of death for ten participants, nine of which died because of cardiovascular complications and one because of multi-organ failure. The range of dialysis survival for the 11 participants who had been surveyed and died during the data collection was 1-7 years. The average survival rate on dialysis treatment was 7.9 years per patient.

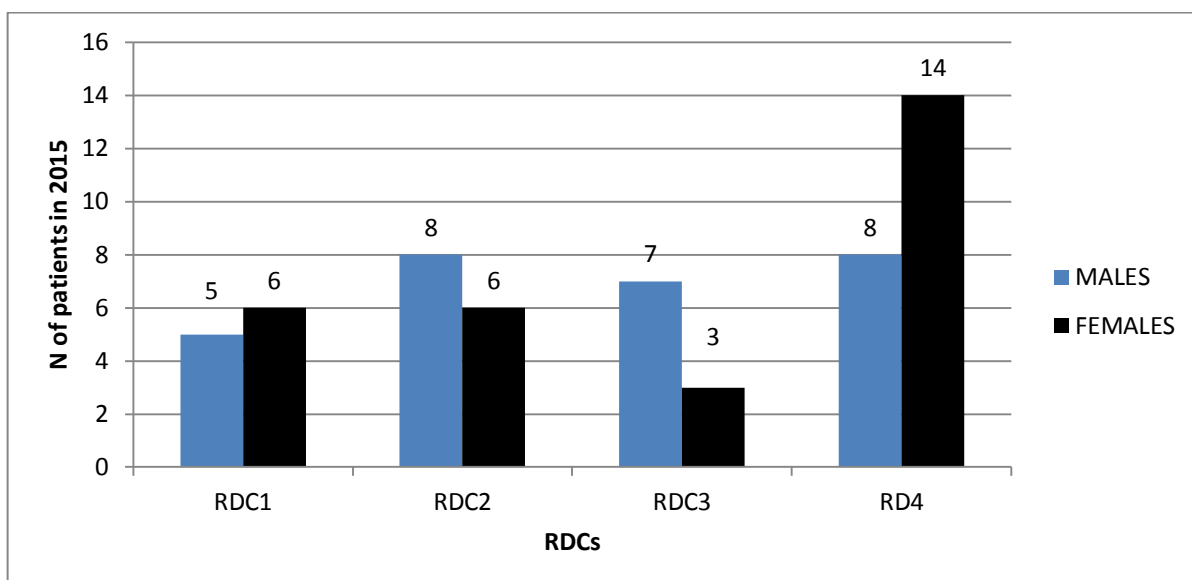


Figure 8-11 Death figures across RDCs in 2015

8.1.9 Participant plans on kidney transplantation

In summary, slightly more than half of the participants ($n = 173 = 50.7\%$) were hoping to have kidney transplantation in the near future. Similarly, nearly half of the participants ($n = 163 = 47.8\%$) were not planning to have a transplantation. Only 1.5 % of the participants were not sure about their transplantation plan (Table 8-17).

Table 8-17 Participant responses regarding their plans for kidney transplantation across the whole sample compared to gender

Variable	Gender		Total n (%)
	Male n (%)	Female n (%)	
Are you planning to have kidney transplantation?			
Yes	104(30.5)	69(20.2)	173(50.7)
No	80(23.5)	83(24.3)	163(47.8)
Not Sure	3(0.9)	2(0.6)	5(1.5)
Total	187(54.9)	154(45.1)	341(100)

More males wanted to have kidney transplantation compared to females (60.1% males vs. 39.9% females - Table 5.21), with no statistical significance difference across subdivisions ($P = 0.124$) or RDCs ($P = 0.124$ – Table 8-18).

Table 8-18 Statistical summary of kidney transplantation plans in relation to the age gender and groups variables across the northern region of Oman

Variable	All	Subdivision 1			Subdivision 2		
Age	Total (n=341) n (%)	All (n=167) n (%)	RDC1 (n=123) n (%)	RDC2 N=(44) n (%)	All (n=174) n (%)	RDC3 (n=77) n (%)	RDC4 (n=97) n (%)
Males	104(60.1)* 80(49.1)**	50(28.9) 44(27)	39(22.5) 30(18.4)	11(6.4) 14(8.6)	54(31.2) 36(22.1)	22(12.7) 22(13.5)	32(18.5) 14(8.6)
Females	69(39.9) 83(50.9)	28(16.2) 45(27.6)	19(11) 35(21.5)	9(5.2) 10(6.1)	41(23.7) 38(23.3)	17(9.8) 14(8.6)	24(13.9) 24(14.7)
Age groups							
0-17	4(2.3)* 2(1.2)**	1(0.6) 0	1(0.6) 0	0 0	3(1.7) 2(1.2)	0 0	3(1.7) 2(1.2)
18-45	58(33.6) 43(26.4)	24(13.9) 25(15.4)	20(11.6) 19(11.7)	4(2.3) 6(3.7)	34(19.7) 18(11)	15(8.7) 12(7.4)	19(11) 6(3.6)
46-64	85(49.1) 75(46)	39(22.5) 40(24.5)	26(15) 31(19)	13(7.5) 9(5.5)	46(26.6) 35(21.5)	19(11) 16(9.8)	27(15.6) 19(11.7)
65-75	22(12.7) 30(18.4)	11(6.4) 19(11.7)	8(4.7) 11(6.8)	3(1.7) 8(4.9)	11(6.3) 11(6.7)	4(2.3) 4(2.5)	7(4) 7(4.2)
>75	4(2.3) 13(8)	3(1.7) 5(3)	3(1.7) 4(2.5)	0 1(0.5)	1(0.6) 8(5)	1(0.6) 4(2.5)	0 4(2.5)
* all first rows are for yes responses ** all second row in each item are for no responses							

It was described that about half (49.1%) of the participants who wanted to have kidney transplantation were in the 46-64 age group. Participant plans across age groups were almost identical across the subdivisions and RDCs. The p-value showed the same conclusion, with no evidence of significant difference between RDCs ($P = 0.174$) or subdivisions ($P = 0.381$) in relation to age groups.

Kidney transplantation plan in relation to education level were tested statistically showing positive relationship. However, the p-value was $P > 0.05$ across subdivisions and RDCs, which indicates no significant statistical difference in this variable in relation to education level between subdivisions or RDCs.

Table 8-19 Statistical summary of kidney transplantation plans in relation to education level

Are you planning to do kidney transplantation?		Yes	No	Not Sure	Total	
Education level	Illiterate	n	68	92	4	164
		%	39.3	56.4	80	48.1
	Read and Write	n	26	25	0	51
		%	15	15.3	0	15
	Primary (1-9)	n	27	19	1	47
		%	15.6	11.7	20	13.8
	Secondary (10-12)	n	39	19	0	58
		%	22.5	11.7	0	17
	College	n	10	8	0	18
		%	5.8	4.9	0	5.3
Post-College	n	3	0	0	3	
	%	1.7	0	0	.9	
Total	n	173	163	5	341	
	%	100	100	100	100	
	% of Total	50.7	47.8	1.5	100.0	

It was noticed that across the subdivisions, smaller proportion of participants in subdivision 1 (45.1%) wanted to have kidney transplantation compared to subdivision 2 (54.9%), but with no statistically significance difference ($P = 0.124$). The highest percentages of participants who planned for kidney transplantation were in District 1 (20.2%), District 2 (13.4%), and District 6 (12.7% - Figure 8-12), with no statistically significant difference ($P = 0.183$).

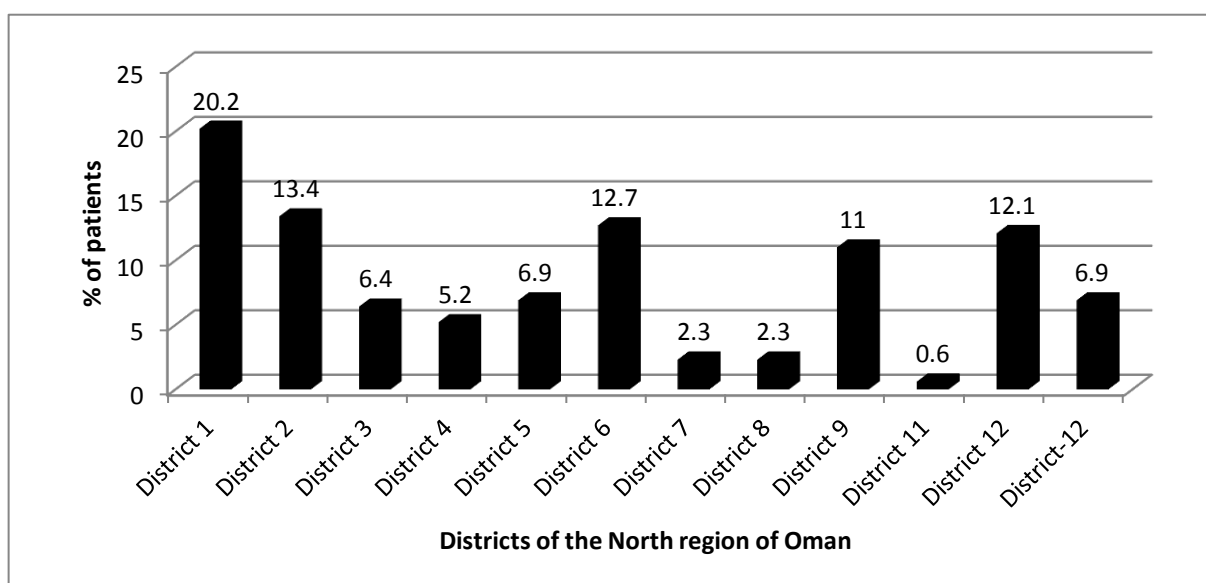


Figure 8-12 Participant plans for kidney transplantation across all districts

9 Discussion of study two

9.1 Participant demography and characteristics

The first objective of this study is answered in this section and sections 8.1.1 by identifying the demographics and characteristics of patients undergoing regular dialysis treatment in the northern region of Oman. In general, both subdivisions and the four RDCs share common similarities, such as having a middle-aged population; nearly half of the population falling within the 46-64 age group, with a mean age of 51.7 (Table 8-1). A recent study from Oman published in 2016, found the mean age of the included treated kidney failure patients overall Oman as 50.1 years old, which agrees with this study's results (Al-Ismaili et al., 2016). In comparison, the common age group prevalence described globally were commonly older groups, especially in the USA (65-74 years) and the UK (70-79 years); in Australia and New Zealand (55-74 years), and in Africa, the common age group was younger (20-50 years). In KSA, dialysis is common in the 26-65 age groups (70%), which include a younger population in comparison to Oman's dialysis sub-population. The higher prevalence among the older age group might be explained as the older age is found to be related to greater decline in kidney GFR and therefore may act as initiating factor of chronic kidney disease but not necessarily a perpetuating factor (Eriksen and Ingebretsen, 2006; Taal and Brenner, 2006). Furthermore, this common age group identified by this study is the upper half of the working age group and the country's economy relies on their contribution. However, the dialysis sub-population identified in this study constitutes only 0.04% of the general population of the northern region of Oman, which is a small proportion. According to mid-2014 statistics, 86% of the general population of the north of Oman is under 45 years old. It is likely that this young educated population can respond positively to an active education program if implemented on them early and frequently.

The general population of both subdivisions had more males than females; however, subdivision 2 had a greater number of males compared to females (Table 8-2). The only two studies published recently about Oman's RRT population had close results with this study's results as follows; this cross sectional study identified 54.8% males vs. 45.2% females, timeline is 2014 – 2015, population is dialysis patients in the northern region of Oman); Al-Ismaili et al. (2016) reported 52% males vs. 48% females, timeline is 1980-2013, population is overall Oman RRT population); Al-Alawi et al. (2017) reported 57.1% males vs. 42.9% females, timeline is 2001-2015, population is overall Oman RRT

population. Though the results of Al-Ismaili et al. (2016) and Al-Alawi et al. (2017) agree and validate this cross sectional results, however, the comparison is handled with caution because of the differences in the timelines and the population covered. Similarly, among the dialysis population of the world and KSA, the number of males was relatively higher than females. Males on dialysis in KSA were 55% compared to 45% females, where 86% of this population were Saudi and the remaining 24% were non-Saudi, in the UK male incidence was 64.6% compared to females, 35.4%. The unexpected part about this part of this study results was that the males who underwent dialysis in subdivision 1 were greater in number than the males of subdivision 2, despite the fact that subdivision 2 had a larger general population and also a larger male population than subdivision 1. This might be investigated in the future to explore the causes and risk factors behind this result, and also behind RDC4 having slightly more females on dialysis than males, and in general having younger males on dialysis compared to slightly older females. However, the general trend for most countries reporting the characteristics of their kidney failure population on dialysis was that the incidence in males is higher compared to females (United States Renal Data System – USRDS, 2013). Taal and Brenner (2006) discussed that there are some contradictions regarding the role of gender in human renal risk. They identified many studies that suggest that worse renal outcomes were seen in the male gender, a higher incidence of proteinuria and chronic kidney disease in males, a higher risk of decline in renal function among hypertensive males, a lower risk of kidney failure among females with chronic kidney disease stage 3, and males with chronic kidney disease had shorter time to start RRT compared to females (Weller et al, 1985; Shulman et al, 1989; Isek et al, 1996; Haroun et al, 2003; Evans et al, 2005; Eriksen and Ingebretsen, 2006).

One study found that women during their reproductive age are less likely to have kidney failure compared to men, and the kidney failure risk start to rise 10 years later in women compared to men (Iseki, 2008). On the other hand, Taal and Brenner (2006) identified a meta-analysis that had 11,345 chronic kidney disease patients from 11 RCTs, which concluded that no increased risk of doubling of serum creatinine or kidney failure alone among men using angiotensin-converting enzyme inhibitor, However, after adjusting the baseline variables such blood pressure and urinary protein excretion, women demonstrated a significantly higher risk of doubling of serum creatinine or kidney failure (Jafar et al, 2003).

Gender differences present in many diseases including renal diseases. Gender differences are identified in the underlying pathophysiology of the disease, in its complications, in presenting variable symptoms of the disease, in responding to the therapy and in tolerance of disease between men and women (Cobo et al., 2016). Gender differences are most likely to be due to some biological or psycho-socioeconomic factors that's need further explorative studies (Cobo et al., 2016). However, the data on this aspect from Oman are limited and therefore needs further exploration and research.

Subdivision 1 had a general population of 61,379 which was nearly half the population of subdivision 2 (102,378). The data showed that 83.3% of the paediatric dialysis patients were from subdivision 2. When the data for the paediatric population is described, it can be seen that 60% of this sub-population reported low socio-economic status, and either kidney problems, SLE, or sometimes both as the primary disease; 80% were males and 50% were from District 6. All of this data requires further investigation to discover the reason underpinning all the paediatric dialysis population coming almost from the same area. The data on paediatric nephrology are limited in general and there were no specific data comparable to this result found; the only piece of information found recently was that the leading cause of paediatric kidney failure in Oman was inherited kidney disease as reported recently by Al-Alawi et al. (2017). However, there are also potential different reasons could explain why most paediatric patients were coming from the same area, such as the type of diet practices that parents follow in this area, or may be biological or socio-economic factors. Also, the main reported causes for kidney failure in the USA for this sub-population were cystic, hereditary or congenital disease, which is almost similar to this study results.

It was expected that there would be more Omani Asians in the dialysis population, because they form the largest portion of the wider population of Oman. However, as explained earlier in the methods of this study, there is no available or reliable data on Omani ethnicity types or characteristics for Oman and for even the Middle East or Arab World. Throughout the literature it was claimed that kidney failure is more common among African-Americans in USA, among Whites/ Caucasians in the UK, and among Caucasians in Australia and New Zealand. A higher incidence of kidney failure was reported by number of population-based studies which was attributable partially to socio-economic and other possible risk factors. This latter might explain the higher prevalence of kidney failure in subdivision 1 (62 kidney failure patients in 100,000 in 2013) compared to subdivision 2 (39 kidney

failure patients per 100,000 in 2013), as subdivision 1 had a higher number of Omani female blacks. Taal and Brenner (2006) discussed that African American race could not act as initiating factor of chronic kidney disease but it could act as a risk factor for chronic kidney disease progression. However, the association between race and kidney failure is not fully elucidated and it could be that some differences in BEINGE factors in relation to the race attributed to the higher incidence of kidney failure among American African for example.

The data shows that the majority of this study dialysis sub-population was able to maintain their marriage, which agreed with the Al-Ismaili et al. (2016) study. Al-Ismaili et al. (2016) reported around 65% out of 4066 Omani RRT registered patients that they were married, and this almost agree with a study from Ghana i.e. 55.7% out of 203 participants were married (Amoako, 2014). Divorce was represented by only 22 patients, eight of whom said they were divorced because of their sickness. This can be understood in relation to the Omani culture, which has strong ties between families and between the members of the same family. This also explains why all of the study population were living with their families, not alone or with friends. This belief is supported by the Islamic guidance toward preserving marriage and family relationships at any cost, and the belief that successful marriage is blessed by God. In general, females tend to maintain their marriages even if they have a sick partner but usually not vice versa. This theory might explain the higher divorce rate among kidney failure females compared to males. The data found in the literature for comparisons on this issue was limited. However, having a chronic illness is a major change on couple's life and surely will have an impact on them. The Caregiver Action Network (it is a nation's leading family caregiver organisation) identified six times higher rate of depression or anxiety symptoms occurrence for family caregiving spouse (Caregiver Action Network – CAN, 2017). Also in a couple of studies, patients with kidney failure showed marital disruption and psychological distress and 20% of dialysis patient spouses showed significant depressive symptoms (Chowanec and Binik, 1989; Cukor et al., 2007). Cukor et al (2007) specified that strain of having a couple with chronic disease may place strain on different marital roles of the couple. Accordingly, this result contradicts the common evidence available in the literature as this study found 62.8% of its population were able to maintain their marriage. Also one study conducted on 116 dialysis patients found that only 38% of the sample were married (Gillespie, 2014), and this again contradicts our results. This implies that the impact of kidney failure on marriage of Omanis could be different due to different culture, different self-behaviour or different set

of socio-economic factors; or happened because some selection bias as the included sub-population is not a nationwide surveyed population and though if this study could include all treated Omani kidney failure overall Oman, there is the possibility of getting some different results.

It was expected that more of the unemployed population would be found in the study population (Table 8-7), but it was unexpected to find that only 21.2% of this population said that they lost their job because of their sickness and commitment to dialysis sessions which could mean that there were other factors that contributed to their unemployment other than their kidney failure problem. Some patients admitted that they received enough support from their employer but were not able to carry on with their work duties due to persistent fatigue and sickness. In the literature, multiple studies with variable degrees of evidence quality (e.g. Lakshmi et al., 2017; Huang et al., 2017; Al-Ismaili et al., 2016; Gillespie, 2014; Amoako et al., 2014; Helantera et al., 2012; Muehrer et al., 2011), reported a high rate of unemployment, especially among dialysis patients. The only study from Oman which reported the employment status of RRT population had almost similar results as one half were unemployed, and less than one-fifth were retired, and others were disabled or unknown status with only less than one-fifth employed (Al-Ismaili et al., 2016). In comparison, one American study found 97% of its haemodialysis sub-population was unemployed and 53.5% of them were disabled (Gillespie, 2014). This cross sectional study did not measure the disability variable which, if measured, would give some rationale for the proportion that were not employed because of disability for example. In one large retrospective study including 102,104 American dialysis patients, the study found that the rate of unemployment of kidney failure patients is high compared to the working-age of the general population (Muehrer et al., 2011). In a Finnish study, which included data from 2,637 RRT patients, found 19% of haemodialysis patients were employed, 30% peritoneal dialysis patient were employed and 40% of the functioning kidney transplant were employed (Helantera et al., 2012). In a Chinese study, which included 231 patients, 49.3% were unemployed (Huang et al., 2017). In an Indian study included 226 dialysis patients, the loss of job was reported in 44% of haemodialysis cohort and reported in 51.2% of the peritoneal cohort (Lakshmi et al., 2017). In another study conducted in Ghana, the unemployed rate was 37.9% out of 203 total participants (Amoako et al., 2014). Factors associated with unemployment status were patient demographic, comorbid conditions, kidney failure cause, insurance status, and predialysis use of erythropoietin and dialysis modality (Muehrer et al., 2011). The participants in this study had an average age of 51

years old which means they did not reach the retirement age, so a potential explanation for their unemployment could be by the multiple comorbid conditions, anaemia or disability and or haemodialysis complications.

Nearly half of the study population were illiterate (Table 8-7), with more illiterate females than males. It was expected to have a proportion of illiterate participants but to have 48.1% illiteracy, this was a high percentage. The degree of illiteracy identified in this research is high compared with some other studies in the literature. One study from Oman did not report illiteracy status specifically but reported education status for overall RRT of Oman which was that around 65% of them had less than 12 years of education, 25% has secondary school and only 10% has a college education (Al-Ismaili et al., 2016). In an American study, there was no illiteracy were reported but the participants who had grade 9 education or less were only 16.8% (Gillespie et al., 2014). In an Indian study the illiteracy reported was 18.6% for the haemodialysis cohort and 15.9% for the peritoneal cohort (Lakshmi et al., 2017). In a study conducted in Ghana, the illiterate proportion was 12.3% of the participants (Amoako et al., 2014). This high illiteracy rate within my study participants could be because the average age of this population was 51.7 years old, which means that many patients were born before the Omani Renaissance (before 1970), before which there was almost no education. Females tend to be illiterate because many of them were married at the era when females were raised to get married and give birth; education was complementary and not essential for females at that time. Males were more educated because that is a requirement to obtain a good job. This is also elucidated by the result that the 18-44 age group in this study were found to be more educated compared to the other groups and this because this group was born after the Omani Renaissance. In the literature there is growing and convincing evidence showing that limited health literacy is common among kidney disease patients and it is linked with number of adverse effects such as higher frequency of missing dialysis treatments and more frequent emergency department visits (Green et al., 2013; Jain and Green, 2016). Accordingly, it is highly recommended that renal health provider be aware of any red flags of limited health literacy (e.g. non adherence with medications or treatments) and at all instances use a clear health communication principles with their patients (e.g. explain things clearly in plain language – Jain and Green, 2016).

9.1.1 Participant distribution across districts

The data from this study showed variations in kidney failure distribution across regions and districts as of the northern region of Oman, also similar results demonstrated in many renal registries' data. Similarly, a study included 719 Australian kidney failure patients from January 1993 to December 1998, found marked regional variation in the incidence of kidney failure across indigenous Australians (Cass et al., 2001). The study revealed inequitable access to dialysis facilities for remote patients and even in urban patients if age and gender were standardised (Cass et al., 2001). Another study conducted in Libya found higher rate of kidney failure incidence in the South of Libya compared to the other regions of Libya. The possible explanation underpinning regional variation in Libya was that the South of Libya is a remote, populated and deprived area with hot and dry weather and occupied by a mixture of different minorities (Alashek et al., 2012). Also potential differences between remote and rural contexts were reported in some studies such as rural areas have lower health levels due in general to differences in demographics, health needs, geographical isolation, type of social relations within rural locale and local health actions, social structures and power (Home Parliamentary Business Committees, 2007; Mariolis et al., 2008; Bourke et al., 2012). A German study, identified that CKD is higher in Northeast than in Southern Germany, due partly to the higher presence of risk factors such as obesity, type 2 diabetes and hypertension in Northeast than Southern Germany (Aumann et al., 2015). In another large scale study conducted in Taiwan in 2009 (n=1,544,82) and 2010 (n=1,669,436), the study concluded that the existence of substantial geographic variations across 368 townships in Taiwan could be the reason behind the presence of regional variations, however, this were not very clear and needed further investigations (Yap et al., 2015).

Geographical or regional variations in incidence and prevalence of kidney diseases and failure are presented widely in the literature and this study results agree with these variations. The reasons behind these variations were variable too, from inequitable access to treatments to variations in the presence of risk factors. There is insufficient data on the reasons for the regional variation in Oman and, this needs further studies to explore them/. However, there are two Omani studies published recently (i.e. Al-Ismaili et al., 2016 and Al-Alawi et al., 2017) which highlighted the epidemiological status of kidney failure in Oman in less depth than in this present research study and so both studies had no regional data provided to compare this research study data with. Also, it is important to note that regional variations presented in this present cross-sectional study do agree with the data

presented earlier in the study one (i.e. the secondary data analysis study) of this thesis (see section 4.3.1 on p.97). accordingly the sample recruited to this study appears to be representative of the larger kidney failure population of Oman and the role of the statistical chance to deviate the data in this study from the truth is low. However, the chance of having underreported cases of kidney failure into the renal health of Oman is possible, which means that the included sample of this study could be an estimate and the real number is obscured.

The data on the Omani population living in the north region of Oman showed that the Omani population of subdivision 2 was about two thirds of the entire population of the north region of Oman ($n = 446,444 = 62.2\%$ -Table 7-2). This could be the reason behind sending some of the District 6 patients to the subdivision 1 RDCs, especially as the highest Omani population among all the districts of the north region of Oman were living in District 6 (Table 7-2). District 6 is also the last district in subdivision 2 on the map, and it is the adjacent district to subdivision 1 area. Nevertheless, this raises doubts over why the population of District 6 did not have their own dialysis centre. The data shows that the highest numbers of dialysis patients were coming firstly from District 1, and secondly from District 6. As a result, there were two dialysis centres in District 1, but none in District 6.

Accordingly, there is more to be done, the dialysis patients are in need of more dialysis centres close to their place of residence as some of these patients were travelling a more than 100 km (about 62 miles) return trip three times a week. The dialysis population are known for their high co-morbidities and dialysis complications, which means that these patients are at risk if they drive on their own, especially after their dialysis session. This again means that the patient will need somebody, a relative or a friend, to take him/her to and from the dialysis centre, which is very difficult to accomplish if the distance to the RDC is far. The paediatric population also needs a nearby RDC to be able to keep up with their school attendance and duties. Some patients also need a nearby RDC because they live in remote and difficult to travel places; otherwise they need to be afforded alternatives such as training to do peritoneal dialysis or haemodialysis at home. There is no known protocol or policy governing the distance allowed for patients to travel from home to a dialysis centre, but the UK can be taken as a good example where there is satellite RDCs close to patients' homes and even transportation is offered in some instances by the RDC itself to its population in UK.

9.1.2 Participant risk factors, causes, primary diseases and co-morbidities

This section answers the study objective related to identifying the common risk factors, causes, primary diseases and co-morbidities of dialysis sub-population of the northern region of Oman. Accordingly, hypertension and diabetes were notable risk factors, causes, primary diseases and co-morbidities across the board in this study. The data from the Omani Ministry of Health agree with this study data. The MOH non-communicable diseases (NCDs) detection programme (testing 15,241 persons above 40 years old in 2013) shows that 18% had increased blood pressure (BP) of more than 140/90 mm/Hg, and 4.1% had missed data; 9.5% had a fasting blood sugar level of ≥ 7 mmol/ml, and 5.9% had missed data; 4.9% had an eGFR of less than 60 (ml/min/1.73m²), and 7% had missed data. The same data shows that the highest detected BPs were in the west end (24.8%), the west (21%), and east 2 (20%); the highest fasting blood sugar levels were in the west end (14.8%), middle (12.3%), and north 2 (11.6%). Also, the highest body mass index (+30) were recorded in the south (60.1%), west end (44.1%), and middle (37.5%). However, the generalisation of this MOH study results should be handled with caution, as the sample used in this programme was a convenience sample (i.e. not randomly selected but people who were available and persuaded to approach the health institution for the screening programme). The MOH, as reported in the Vision 2050 report (see Health sector in Oman, p.73), is aware that NCDs are increasing, knows that such risk factors as hypercholesterolemia, and being overweight or obese, are increasing among Omani population, and knows that 52-75% of the hypertensive diabetic population do not know their increased levels of BP and blood sugar (Ministry of Health/Oman - MOH, 2014). However, the issue now is to know where the lack is and why, despite the efforts of the MOH to fight NCDs, the population is still denying their NCDs and reluctant to approach health institutions for treatments.

Different risk factors should be investigated in the Omani context, such as the congenital and genetic predisposition of the Omani population, nephrotoxin use, cultural factors, socio-economic status, limited access and late referral to health institutions, health beliefs, and why males are reporting more NCDs. All this will help to identify the risk factors and their relationship to the NCDs so that proper plans can be put in place to reduce them, such as preventive programmes and perhaps also curative programmes. Taal and Brenner (2006) discussed the role of number of risk factors in either initiating or perpetuating chronic kidney disease/ kidney failure. The main roles identified were as follows: diabetes was

related to a substantially increased risk of kidney failure or death related to chronic kidney disease; in many large population-based studies, hypertension was predictive of kidney failure; micro puncture studies have evidenced the relationship between obesity and glomerular hyper filtration and glomerular hypertension which can aggravate the progression of chronic kidney disease; some studies suggest the role of genetic factors in increasing the vulnerability to early manifestation of chronic kidney disease; a substantial body of evidence exists in supporting the theory of that low nephron endowment predisposes individuals to chronic kidney disease by escalating the single nephron GFR, and therefore, reduce renal function; GFR can be increased by protein feeding and thereafter accelerating renal disease progression; nephrotoxins such as cigarette smoking which were identified as an independent factor for different manifestation of chronic kidney disease (Zatz et al, 1985; Bosch et al, 1986; Iseki et al, 1996; Haroun et al 2003; Luyckx and Brenner, 2005; Hsu et al, 2005). These main roles can be investigated further in the Oman context and so then this will contribute to the knowledge base of renal disease and will help to pave the road for further improved health care.

This study shows higher percentages of hypertension, obesity and diabetes in District 6, District 1 and District 2, and this was expected, as the highest populations of treated kidney failure come from these districts which imply a relationship between these causes or risk factors (i.e. diabetes, hypertension and obesity) and occurrence of kidney failure in these particular districts. However, it was noticed that hypertension is higher in subdivision 1, which has less population, and this unexpected result should be investigated further. This result agrees with the data of the KSA and European populations.

In the literature, there was wide agreement across the board on diabetes and hypertension as the primary causes for kidney failure (among the KSA dialysis sub-population 38.8% had diabetes and 39% had hypertension). In comparison to the data from Oman, one recent study (i.e. Al-Ismaili et al., 2016) reported that the primary causes of RRT the Omani population were respectively glomerular nephritis (35%); diabetes (28%), hypertension (18%) and other causes (19%) while the same study reported the main leading causes among dialysis sub-population were respectively diabetes (46%) and hypertension (22%) which support this study results.

In the literature, the most common co-morbidity was cardiovascular diseases, which was the third most common co-morbidity after diabetes and hypertension in this study. The common co-morbidity among Omani kidney failure patients are the same as most renal

registries population. Al-Ismaili et al. study (2016) reported the same co-morbidities as hypertension (87%), diabetes (58%), ischemic heart diseases (27%), and cardiovascular diseases (3%) among Omani Kidney failure patients. However, there are some variations in the percentages of the two studies because the measurement scale is different as they measure (i.e. Al-Ismaili et al., 2016) for the whole country and this present study measure the co-morbidities of the dialysis sub-population for the northern region of Oman only. Also this present study conducted in 2014-2015 while their study covered a different timeline, which was 1980-2013. Furthermore, this present study had an option for combined diabetes and hypertension while Al-Ismaili et al. (2016) measure each disease individually. Also multiple co-morbidities are a common characteristic among dialysis sub-population. Yet the control of the multiple co-morbidities for the dialysis population is extremely challenging, and it requires a multidisciplinary team to coordinate and control them. Finally, the kidney failure risk factors, causes and co-morbidities are not studied with rigorous research designs such as randomised control trials, so further evidence is needed to enhance these conclusions.

9.1.3 Participant haemodialysis characteristics

This section answers the study objective related to describing the present dialysis modalities and the characteristics of haemodialysis modality of the sub-population of the northern region of Oman. This study's data shows that the appropriate investigations for detecting kidney disease in the current dialysis sub-population of the north region of Oman were in place and accessible for all patients. However, there were many patients who did not know what eGFR test is, or if it was done for them or not. Also, many participants said that their urine was taken for kidney disease diagnosis, but no result was reported back to them. The participants would have welcomed any information if they had been told. This is again is linked to the health literacy issue discussed earlier. Increasing health literacy of the patients is a paramount pillar toward improving compliance and accordingly treatment outcomes.

The common vascular access in the KSA dialysis sub-population was AVF (65%), which is similar to what was found by this study. In KSA, there were 16,897 dialysis patients (547 pmp) by the end of 2015, 15,560 patients on in-centre dialysis and 1,307 on peritoneal dialysis. In the north region of Oman nearly all the surveyed participants were undergoing

in-centre haemodialysis because there was no other alternative offered to them. Since there is insufficient evidence to support convective dialysis (HF, HDF, and AFB) over traditional haemodialysis, it is convenient for the MOH of Oman, at present, to keep running the same regimen of traditional haemodialysis. However, conducting research to test these different modalities and their outcomes on Oman's dialysis population could contribute to the evidence and help the MOH to make better decisions on patients' treatment plans.

Currently, the dialysis population of Oman have one common dialysis option, which is in-centre haemodialysis. Similarly, greater than 80% of dialysis sub-population of the USRDS (2015) participant countries (53 countries) was following in-centre haemodialysis except in Hong Kong and New Zealand. Peritoneal dialysis is an emerging option which can grow if a training team is made available for the different RDCs of Oman to train and describe patients; this could be the best option at present for the dialysis population in Oman. Peritoneal dialysis patients should be prescribed with a personalised, adequate dose of peritoneal dialysis and with observation for infections. Home haemodialysis is not yet offered for this sub-population in Oman. This option, if offered, would open a door of hope, especially for the young population on dialysis to have more freedom and control over their lives.

This study found that 78.3% of dialysis patients started their haemodialysis immediately, or within three months after diagnosis, because these patients sought medical attention only after progressing to a critical condition where they could not tolerate the symptoms any longer and accordingly had to start dialysis as soon as possible. Many patients reported their numerous medical consultations either in Oman or in other countries to confirm their kidney failure, as they were denying having kidney failure.

Nearly two thirds of the patients were attending three haemodialysis sessions per week. Subdivision 1 had more patients attending three sessions and subdivision 2 had more attending two sessions, because this latter had more dialysis sub-population and therefore less capacity to accommodate three dialysis sessions for all patients. Despite the recommendation of the three haemodialysis sessions per week for the average patient protocol, this area needs further investigation to confirm that this is an adequate and safe dialysis dose. Furthermore, the nephrology team should be careful to base a patient's dialysis dose on a comprehensive assessment of the patient using monthly blood tests, pre-

and post- dialysis parameters, and the general health status of the patient as explained in chapter one.

Across all the RDCs, nearly two thirds of the dialysis patients had AVF vascular access, which is the one recommended for this population because of its better outcomes. The interesting thing is that the AVF and AVG patients were the most patients who expressed their comfort with their type of vascular access, while all remaining patients with other vascular access reported discomfort (13.5% - Table 8-14). This results guide the nephrology team to try their best to provide AVF access whenever possible for their dialysis patients, and to try to create the vascular access 3-4 months prior to initiating dialysis, as recommended. However, these patients should be always watched for complications of AV access such as infection.

The participants were comfortable with morning or afternoon dialysis sessions, but they were upset if shifted to night sessions. This was the reason behind the less than 90% satisfaction rate at RDC1 and RDC4, because these two RDCs were the ones offering night dialysis sessions.

9.1.4 Participant perceptions on the impact of dialysis treatment on their lives

It was unexpected that over 80% of this study participants reported that dialysis had not caused them stress or worry and that it had little financial impact on their lives which imply better QoL for this study population. In contrast to this study results, the literature has repeatedly reported a reduction in QoL of CKD and kidney failure patients. A study conducted on 155 patients' stages 1-5 of CKD and 36 patients on haemodialysis concluded that QoL reduced in all stages of kidney disease (Cruz et al., 2011). Another cross-sectional study was performed on CKD patients stages 4-5 (151 patients) who receive either peritoneal or haemodialysis treatment concluded that the sample studied demonstrated compromised QoL scores (Abdel-Kader et al., 2009). One more cross-sectional study assessed for health-related QoL for 535 patients with CKD stages 2-5 and 55 controls found significant deterioration in health-related QoL with the lowest scores in CKD patients stage 5 (Pagels et al., 2012). Though the concept of QoL is controversial, the WHO (2009) has defined it as "an individual perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals,

expectations, standards and concerns". Accordingly, possible explanation for this study population showing better QoL compared to other studies from literature could be because these participants had psychologically and mentally reached the adaptation and comfort stage. It could be that they have strong faith (religious/spiritual) that this is their destiny and nothing better can be done, and therefore perceive the reduced of QoL as something good though. Santos et al. (2017) in their evaluation for 161 patients undergoing haemodialysis provided an evidence suggesting the association of religious/spiritual coping methods with QoL and depression among haemodialysis patients. This evidence identified positive correlations between religious/spiritual coping scores and general health and vitality scores (Santos et al., 2017). The Santos et al. (2017) evidence supports the finding of this research that implies positive religious/spiritual status can positively affect the QoL of haemodialysis patients. However, is the religious/spiritual factor is the main factor can affect the QoL of Omani haemodialysis patients or there are a collection of factors (e.g. family and friends support that if stands all together, they can improve the overall QoL of the Omani participants of this study. Families in Oman provide great support to their sick members, which may be a factor that helped many patients in improving their mental and psychological status. Also, his majesty Sultan Qaboos provides a monthly allowance for this population that is around £200/month. This allowance helped to sustain the financial status of these participants. On the other hand, the participants of this study who reported a greater impact of kidney failure and RRT on their lives should not be neglected (**Table 8-16**Table 8-16), and the support needed must be provided to them. Also, the proportion who reported lower QoL should be investigated to understand their perception of QoL and the reasons underpinning their QoL reduction so these reasons could be resolved in the future (Figure 8-8). At all instances the perspective of QoL for Omani kidney failure patients is not explored sufficiently in this study and needs further study and exploration.

This section aimed to explore the haemodialysis treatment impacts briefly on the haemodialysis patients in the northern region of Oman. It is only to have a flavour if there is a presentation of negative impacts on the QoL of this population and thereafter recommend doing further research on this aspect depends on the findings. It is unlikely that the contradicting results of this present study are due to chance, bias or such confounding factors but it is more likely that the contradictory results obtained were as a result of some limitations in the survey design itself. The usage of the scale of yes or no helped apparently to obscure the real truth and provided contradicting results to the reality. The original

questions from the KDQOL-SFTM 1.3 use a Likert rating scale distributed into five degrees (i.e. definitely true, mostly true, don't know, mostly false, and definitely false). The use of the same Likert rating scale could give the obtained results more of normal distributed values and also would validate this part of the survey. Also, researchers can debate that the author may have some impact on the participants' responses and therefore, they may answered positively to please the author. However this perspective is greatly affected by the size of distance/closeness of the author with the participants, and how much information (e.g. race, class) and relationship, the researcher shares with their participants (Al-Natour, 2011). In general, relationships and closeness are usually developed inside qualitative research and since this research was purely quantitative so the contact time with participants was short and did not allow for deep impacts on the participants responses.

9.1.5 Participant death profile in 2014 and in 2015

Due to the high vulnerability of dialysis patients, death is an expected outcome. Although efforts are being made to increase the lifespan of the general population as well as that of kidney failure patients in Oman, this however could increase the size of the kidney failure population (prevalence) without guaranteeing a decline in the death figures. This perhaps explains the increase in death figures in this study population, which was 42 in 2014 and then 57 in 2015. Cardiovascular disease was the major cause of death in this population, which agrees with the data of many countries. A systematic review identified 39 studies that included 1,371,990 participants concluded that individuals with CKD are at high risk for cardiovascular disease and all-cause mortality (Tonelli et al., 2006). These review findings were consistent across all studies despite differences in design and study population (Tonelli et al., 2006). In 2013, kidney disease killed more than 47,000 Americans (National Institute of Diabetes and Digestive and Kidney Diseases, 2016). In a Swedish study that included 3040 CKD patients' stages 4-5, 725 peritoneal dialysis patients, 1791 haemodialysis patients, and 606 transplanted patients; the study concluded that the dialysis patients were at the highest risk of mortality, peritoneal dialysis patients had considerably lower mortality risk compared to dialysis patients, and least mortality risk was for kidney transplanted patients (Neovius et al., 2014).

On the other hand, dialysis treatment can prolong survival of kidney failure patients if compared to conservative management despite dialysis treatment's poor prognosis (Thadani, 2013). Survival duration is affected by number of factors such age, functional status, co-morbidities status (Thadani, 2013). Survival duration of Omani kidney failure patients' cannot be improved and extended unless all-factors relevant to this population treatment are improved and consequently improving their QoL. Accordingly, there is an urgent need to gather in depth data regarding these population treatments, treatment outcomes, survival durations and life expectancy and QoL status.

9.1.6 Participant plans on kidney transplantation

This study identified an association between the education level of the participants and their desire for renal transplant, which was interesting to explore further and is therefore discussed individually in the following chapter.

10 Participant plans on kidney transplantation

More than half of this study's participants wanted to have kidney transplantation, which is expected (Table 8-17). Papers published on testing the desire of kidney transplantation of dialysis patients found either limited or of older dates. The limited available evidence agree that the desire for kidney transplantation decreases in aged patients (Fukunishi, 1993), and African American women tend to have less desire to undergo live donor kidney transplantation compared with African American men (58.5 % females vs. 87.5% males – Gillespie, 2014). The literature evidence supports what this study found as most of those who wanted to undergo kidney transplantation were males (60.1%), and also the desire for kidney transplantation declined with aging (12.7% yes response vs. 18.4% no in the age group 65-75 years old, and 2.3% yes vs. 8% no in the age group over 75 years old). The possible explanation is that men are most likely to take more operational approach toward their health care compared to women (Hunt et al., 1999; Baines and Jindal, 2003). Also low self-esteem and lack of strong social support among women could contribute to the lower desire of kidney transplantation among women (Hunt et al., 1999; Baines and Jindal, 2003). Omani women are usually had good self-esteem and good social support but it could be because they are less health conscious of kidney transplantation optimal outcomes. The older age patients tend to say no for kidney transplantation because of their psychosocial defence mechanism mainly denial (Fukunishi, 1993). Also one more possible explanation which the author described while in clinical practice for 18 years was that older patients tend to reject any treatment involving major surgery because they fear that they are going to die during the surgery.

When kidney transplantation desire was associated with education level, it was noticed that as the education level increased, the desire for kidney transplantation increased (Table 8-19). For example, every single participant in the post-college group wanted transplantation. However, in the illiterate group the proportion of participants who reported no desire for kidney transplantation was higher (56.4%) than those who wanted to have kidney transplantation (39.3%). In the literature, there were no studies found to examine specifically the association between the dialysis patient's level of education and their desire for kidney transplantation. However, there were some studies which tested the association between education level or health literacy and some other outcomes such as chronic diseases. Overall the evidence testing the relationship of education or literacy level with other outcomes under investigation is mixed in their conclusions, and varied in their evidence degree of strength. However more weight of evidence support the positive

association between the high level of education and good health. In an observational cohort study included 61,457 participants; the study found the higher educational level was independently associated with lower prevalence of chronic diseases (Choi et al., 2011). In a systematic review included 111 research articles; the review found low health literacy is associated with poorer health outcomes and poorer use of health care services (Berkman et al., 2011). The evidence coming from the research articles included in the systematic review (i.e. Berkman et al., 2011) were rated as good or fair evidence after two reviewers independently rated the quality of the evidence using predefined criteria. In another study included 62 Black and White haemodialysis patient aged 18-75 years old, the study found inadequate health literacy among them; also 78% lower hazard of referral for transplant evaluation were reported among the participants who has inadequate health literacy (adjusted hazard ratio [AHR] 0.22; 95% confidence interval 0.08, 0.60; $P = 0.003$ - Grubbs et al., 2009). Also in one literature review paper, the review reported limited health literacy as one barrier to kidney transplantation (Jain and Green et al., 2016).

One potential mechanism of positive relationship between high education level and willingness to undergo kidney transplantation could be that these patients are more likely to educate themselves about the best treatment options (in this instance kidney transplantation) available to them even in the absence of the medical advice. Therefore, the higher education participants made a decision to undergo kidney transplantation based on their higher level of health literacy that related to their higher education level. However the high level of education could appear independent factor of association, statistically, while in reality it is not because of presence of other confounding factors that were not measured in this present study such as young age. In a study included 295 dialysis participants who were 71.5% of them were male and the mean age of the all participants was 44.53 ± 12.09 years, the study identified some factors associated with renal transplantation desire namely younger age (<45 years) (OR = 2.14 CI: 1.12 - 4.06 $p = 0.02$), longer median duration on dialysis (>34 months) (OR = 2.12 CI: 1.15 - 3.88 $p = 0.01$) and the Christian religion (OR = 0.43 CI: 0.20 - 0.92 $p = 0.03$ (Lagou et al., 2017). Also, the incorrect estimate of association can happen because of selection bias of participants, those participants who are not representative can deviate the results from the truth. The selected participants of this study are representative because all patients on dialysis were included. However, it is hard to claim that this result is generalizable to the entire population of the country because of the geographical limitations of this study to the north of Oman only. The statistical chance to estimate incorrect association is present because the unclear effect of the confounding factors which were not explored by this present study such as young age.

However, kidney transplantation success is not sustained in Oman at the moment because mainly the variation in incidence and prevalence and organ availability. The major barrier toward the increasing success of kidney transplantation in Oman, described by this study, is kidney shortage. Therefore organ donation campaign should be launched in Oman though making active educational programs to spread all necessary information about organ donation across the public. It is important to start organ donor register that accessible by public and be transparent about the organ donation and transplantation through publishing the main statistics and the main activities of this aspect.

Additionally, not all patients are eligible for kidney transplantation, and this should be explained very clearly for non-eligible patients. The UK has succeeded in providing more than half of the kidney failure population with kidney transplantation; Oman can learn from their experience to increase the number of kidney transplantations annually. It was expected that young age patients and highly-educated patients would have a higher demand for kidney transplantation, and this is what the data from this study verifies. Patients of subdivision 2 wanted kidney transplantation more than those in subdivision 1, and this is because the population living in subdivision 2 are generally younger and better educated.

11 The comprehensive discussion on the significant results

This quantitative mixed method study was mainly conducted to have a deeper understanding of the Oman RRT population. The main aim was to identify the epidemiological variables of the Oman RRT population, and status of publishing on this population. Two designs were used to gather the necessary data, which were secondary analysis of existing data coming from RRT register and published resources, and cross-sectional design. Most of the data from the first design were retrospective data covering aspects such as the nephrology care development, publishing status, and epidemiological variables of Oman RRT population from 1980 and until 2015. The second design was used to gain initial understanding of the characteristics of the Oman dialysis sub-population through surveying a cross-sectional sample that on dialysis in the northern region of Oman on years 2014 and 2015. Most of this design's data were prospective gathered through researcher administered survey.

The main conclusions of this thesis are mainly tied to answering the six major research questions of this thesis. First research question was related to the development of Oman renal replacement therapy. From the data gathered by the secondary data analysis study, it is known that nephrology care in Oman began in 1980, initially through the efforts of non-Omanis and thereafter by Omani nephrologists. The first RDC opened in 1983 in Al-Nahda hospital with seven haemodialysis machines, treating 35 patients. The first remote RDC was established in District-1 in 1991. The main central RDC in the capital was established in 1998. The RRT services had developed in a steady and good manner in Oman to reach 18 active RDCs and 217 dialysis station across the country by the time this study was concluded at end of 2015. However, the comparison of the dialysis station ratio to the served patients showed that the load of the performed dialysis sessions per week in the described RDCs are more than recommended by the ASN dialysis curriculum and accordingly this imply that the demand for dialysis is more than the available supply. Another conclusion is that if the Oman MOH plans for further RDCs, it would be helpful to consider that these RDCs should be closer and accessible by patients, especially in the most densely parts of Oman like the capital and the northern region. In consideration of the complex geography of Oman, it is supportive from Oman's MOH to facilitate transportation if possible for this sub-population and to offer them life insurance as they utilise the traffic more frequently than normal people.

Further to answering the first research question, a kidney transplantation program was absent in Oman until 1988. From 1980-1988 the patients eligible for kidney transplantation were sent abroad to receive the surgery and kidney transplantation care. In 1988, the Oman transplantation program was established. In 2005, the transplant coordination unit and kidney donor clinic were launched and as a result the average of 6.5 kidney transplants per annum was increased to 23 kidney transplants in 2009. Also sometimes these transplantation rates are not sustained and can be less than these rates. However, the data from USRDS annual report (2015) show that Oman had transplantation rates of 18 pmp per annum, which is again the same conclusion of this study, that Oman has one of the lowest rates of kidney transplantation in the world compared to best rates of kidney transplantations performed by countries like Croatia (59 pmp), Netherlands (56), USA (56), and UK (51). However, and to be realistic, Oman MOH has secured the fund and the kidney transplantation infrastructure in place (see Kidney transplantation in Oman (1980-2013)). The shortage appeared in the number of kidney donors and this needs hard work toward increasing the awareness of the public regarding the importance and goodness of kidney donations. The literature review revealed that only 35 % (304 participants) of Omanis would donate organs after death in Oman. The literature and this study recommended an urgent education and awareness program about organ donation especially among school and university students.

The second research question was regarding Oman dialysis and kidney transplantation statistics. There were 2,069 RRT (i.e. both dialysis and kidney transplant treatments' cohorts) treated patients' alive on 31st December 2013 and 2,192 alive patients on 4th November 2014 distributed as follows: haemodialysis cohort had 1,161 patients (52.9%), the peritoneal dialysis cohort had 76 patients (3.5%), and the cohort who had functional kidney transplants had 955 patients (43.6%). The RRT prevalence was 549 pmp in 2014. The first comprehensive statistics available were for dialysis treatment for the years 1983, 1985 and then from 1998 to 2015 (Figure 5-3). The dialysis treatment increased from 35 dialysis patients in 1983 to 1,439 dialysis patients in 2015, which is a 4,010% increase in the 32-year- range (i.e. 1983-2015). The mean prevalence for dialysis treatment across the years of 1983-2015 was 724.9 treated patients per annum. This study found the prevalence rate for dialysis treated patients in 2015 was 61.4/100,000 (i.e. 614 pmp) per Omani population or 34.6/100,000 (i.e. 346 pmp) if calculated across the total population. In comparison, the prevalence rate for dialysis treated patients was 59/100,000 (i.e. 590 pmp)

Omani population or 33.2/100,000 (i.e. 332 pmp) per total population in 2013, which showed an increase in the prevalence of dialysis treatment in between 2013 to 2015.

As has been said, it is favourable if the MOH consider publishing precise statistics on different categories like Omani under RRT (while separating statistic of dialysis from kidney transplantation), non-Omani under RRT, kidney transplantation in total, kidney transplantation from living kidney donors and from deceased kidney donors, number of patients under different modalities like haemodialysis and peritoneal dialysis, incidence, death figures and causes of death, paediatric statistics under RRT, and the rough cost of RRT treatment per annum. These statistics will help future research to grow and will aid renal researchers in planning for further research beyond the observational designs, for example, experimental designs. Other suggestions are first to activate the research studies department in the MOH by providing training for those concerned on the best research topics and designs needed by the MOH and the best research quality assurance practices that should be maintained by researchers while conducting research studies. Also, to create an expert editorial panel, on Oman MOH level, to review and professionally edit health research articles in the shortest time prior sending to high impact factor scientific journals. The panel should undergo regular training and assessment of their skills. Also, the panel can be in affiliation with other rigorous experts from high impact journals. This act will improve the quality of health publication coming of Oman and will improve the Oman MOH publication standard and rate.

Further results answering the second research question is that in 2010, the highest prevalence rate for dialysis treatment was in the capital at 71.3 dialysis-treated patients per 100,000 Omanis or 37.4/100,000 per total population, and the lowest was in the west at 30.3 dialysis-treated patients per 100,000 Omanis or 23.7/100,000 dialysis-treated patients per total population. In 2015, the highest prevalence was in the west end at 99 dialysis-treated patients per 100,000 Omani populations, or at 49.5 per 100,000 total populations. The lowest prevalence was different for the Omani population compared to the total population. For the Omani population the lowest prevalence was in the north at 46.8 dialysis treated patients per 100,000 Omani populations, and for the total population for the lowest prevalence was in the capital at 30 dialysis treated patients per 100,000 total populations. The statistics of RRT incidence were available for the years 1983 to 2015. The number of new patients registered in 1983 was 34, and in 2015 were 230 patients for Oman, which is a 576% increase in incidence in the 32-year range. The incidence rate

increased from 2.29/100,000 (22.9 pmp) treated kidney failure patients in 1986 to 4.36/100,000 (43.6 pmp) treated kidney failure patients in 2013 to 5.5/100,000 (55.3 pmp) treated kidney failure patients in 2015. The Oman's RRT register reported a grand total of 3,504 new kidney failure patient since 1983-2010 (28 years), which gives mean incidence rate of 125 treated kidney failure patients per year per total population of Oman. The diabetic nephropathy incidence for Oman was only two patients in 1983 and 94 patients in total by 2010. Diabetic nephropathy increased from 38.6% in 2006 to 47% in 2009 and then dropped slightly in 2010 to 45%. There were no data on the incidence of hypertensive nephropathy in the register.

From these results and from the USRDS annual report (2015), it is concluded that the incidence and prevalence of treated kidney failure in Oman is considered among the lowest rates. On the other hand, the rates of diabetes, which is a major risk factor and cause of chronic kidney diseases is alarming in Oman, Oman is among the 8th highest countries (i.e. among 53 participant countries of the USRDS, 2015) having diabetes. The diabetes rates if not reduced and managed well in Oman, logically will lead to increasing figures of treated kidney failure in Oman and will increase the direct cost to be more than 9,543,572 OMR (~20 million GBP) that's reported in 2015, which is 325% increase over a 17-year period in Oman. Also, the predisposing factors of diabetes in Oman need to be explored. In theory and in relation to chapter two, the high rates of diabetes in Oman could be related to one or more than one of the PESTLE or BEINGS factors. For example, Oman is high in-income with rapid economic growth and this may affect people's attitude toward many life practices, for example, reduction in physical activity due to use of mobile vehicles and employing house maids and the increase in using mobile phones and increasing on-hands use of technologies. Also other impacts of environmental and other factors on Omanis need to be investigated such as the impacts of the topographical nature (e.g. do the population living across the coastlines have higher rates of CKD compared to the interior population?), climate, dry weather and purification of water on Omanis health; the impact of the progressing health technologies on patients' rates of mis-diagnosis or late referral.

The number of RRT treated patients who died between 1983 and 2013 was recorded as four deaths in 1983 and 77 deaths in total by 2013. The highest death figure reported at 114 deaths in 2009. The overall trends were showing fluctuating increase in death figures with common reported cause of death as cardiovascular diseases. The main reported causes of death across this population were cardiovascular disease (24.5% in 2001-2010) and

infection (26.6% in 2001-2010), however, there were many cases where the cause of death was unknown (31.3% in 2001-2010) as the patients died at their homes and the disease register did not capture the cause of the death. The non-reported causes, cardiovascular disease, and infection account for 82.4% of death in 2001-2010 of this population in Oman. The common cause of death of RRT population in the world was also cardiovascular diseases. It was described that prevalence of all causes of death appeared to be higher in the dialysis cohort (88.5% in 2001-2010) compared to kidney transplantation (9.2% in 2001-2010) and peritoneal dialysis (2.3% in 2001-2010) cohorts. On the other hand, the percentage of deaths within the kidney transplantation cohort decreased from 32.5% in 1983-1990 to 27.1% in 1991-2000 to 9.2% in 2001-2010. Also, the overall death percentages increased from 66% in 1983-1990 to 72% in 1991-2000 to 88.5% in 2001-2010. This observation agrees with the all results reported by all major registries such as UKRR and USRDS. The death figures appeared to be higher in males ($n = 797$) compared to females ($n = 713$) in all treatment modality cohorts except the peritoneal cohort where female deaths ($n = 16 = 59.3\%$) appeared to be higher compared to males ($n = 11 = 40.7\%$). The cost of dialysis treatment increased 325% from 1998-2015.

The third research question was about the pattern that emerged from the gathered statistics. Accordingly, the described pattern showed increase in prevalence; an overall increase in incidence but slight reduction of incidence in 2015 with no clear reason for this reduction but it could be secondary to the national efforts towards fighting the chronic diseases occurrence in the country. Nearly half of the patients in 2015 had diabetes as a primary disease, which alerts the country to the increasing in chronic kidney diseases and kidney failure if diabetes figures are not reduced and managed well.

The fourth research question was about Oman RRT publishing status since 1980 to 2013. So, among the databases searched, 44 articles (see Appendix-F on p.269) focused on or mentioned RRT, kidney failure or chronic kidney disease in Oman. However, the epidemiology of kidney failure was the focus of two (4.5%) national studies only, which are both from the past century. There were five (11.4%) other international studies which mentioned epidemiology of kidney diseases in Oman briefly. Kidney transplantation was the most popular researched topic in relation to this population in Oman ($n = 16$ studies = 36.4%). The remaining articles ($n = 21 = 47.7\%$) were either exploring the risk factors of chronic kidney disease or handling general topics related to RRT, kidney failure or chronic kidney disease in Oman. This data showed that the status of kidney failure publication

coming from Oman is limited. Also, the quality of the past research studies in this field and in the biomedical research in Oman is questionable as most Omani researcher found publishing in journals with either no impact factor or impact factor of less than one.

The fifth research question (see chapter 7 on p.161) identified the following variables: the demographics, distribution across sites, primary diagnosis, risk factors, co-morbidities, and death profile of kidney failure patients undergoing regular dialysis in the northern region of Oman. The cross-sectional study revealed that the average age of this population was 51.7 ± 15.8 (mean \pm SD) and more than 80% of this population were less than 65 years old at the time of the data collection. The greatest frequency of treated kidney failure was in the age group 45-64 years old, but the greatest prevalence was exhibited in patients aged more than 75 years old which is most likely due to improving in survival of these patients. There were more males ($n = 187 = 54.8\%$) to females ($n = 154 = 45.2\%$), males appeared younger with a mean age of 50.3 years compared to the female mean age of 53.3, although this was not a statistically significant difference ($P > 0.05$). However, the general trend for most countries reporting their kidney failure on dialysis population characteristics was that males are higher in number compared to females. Though, the difference in ratio of treated kidney failure Omani males to females is relatively close which goes with the Omani grand total population census where Omani males ($n = 1,143,579 = 50.6\%$) are more than Omani females ($n = 1,117,126 = 49.4\%$, 2014 census). Among the 341 participants of the cross-sectional study, there were 335 adults (98.2%) and six children (1.8%). The majority of the participants were married ($n = 214 = 62.8\%$). The vast majority of the participants were unemployed ($n = 292 = 85.6\%$) with only 62 (21.2 %) participants saying that they lost their job because of their sickness. Forty-eight percent of the participants were illiterate compared to 6.2% who had further education (i.e. college education) or higher education (i.e. university education), with more females illiterate ($n = 103 = 66.9\%$) compared to males ($n = 61 = 32.6\%$). This data showed most of the surveyed patients were married, unemployed and illiterate. Most of married patients got married before they had their kidney failure diagnosed and it was most likely that their marriage survived because of the strong rapport already existed between spouses before the sickness of one of the spouses. On the other hand, the patients who had their kidney failure diagnosed while they are still not married, they mostly stayed un-married. The high rate of illiteracy among the treated kidney failure population of the cross-sectional study may imply that kidney failure is most likely to happen among people who have no or limited education. This can direct the effort to target students in schools and universities to increase their awareness and

knowledge about diabetes and chronic kidney diseases methods of prevention and encourage them to educate their parents and grandparents (i.e. target illiterate people) and therefore wider sector of illiterate people will be reached through the young educated population.

Further to answering the fifth research question, among the 12 districts of then region of Oman, the highest number of participants came from District 1 ($n = 62 = 18.2\%$), then from District 6 ($n = 58 = 17\%$), and third from District 11 ($n = 55 = 16\%$). The smallest number of participants came from District 8 and District-10 ($n = 8 = 2.4\%$) and District 7 ($n = 5 = 1.5\%$). The proportion of male participants were slightly higher than females across all districts except in District 1 and District 3 which had no statistical significant difference ($P = 0.682$). This data indicates that the prevalence of treated kidney failure across the districts were variable due may be to the variations in populations numbers and characteristics. However, this data are important for Oman MOH to view and analyse the variation in number of prevalent patients across the national, regional and district levels to aid the Oman MOH in their capacity planning process. For example, this data showed that there are no RDC serving District 6, which has the second highest number of treated kidney failures among the 12 districts of the northern region of Oman. The patients of District 6 expressed their need for having a closer RDC to their residence area while surveyed in 2014.

The three primary diseases most reported were the following: hypertension ($n = 161 = 47.5\%$), diabetes ($n = 77 = 22.7\%$); and diabetes and hypertension combined ($n = 55 = 16.2\%$). Hypertension was the risk factor reported most frequently by the participants (14.2%); second was obesity (11.5%); third was diabetes (8.6%). The most common co-morbidities reported by these participants were hypertension and diabetes together ($n = 156 = 32.4\%$). The death figures for 2014 and 2015 respectively were 42 and 57 patients in total per annum across the four RDCs. The main cause of death reported by the four RDCs of the northern region of Oman were cardiovascular diseases ($n = 41 = 41.5\%$) and infection ($n = 10 = 10.2\%$). Nearly half of the participants had been on dialysis for five years at the time of data collection ($n = 165 = 48.4\%$). The most popular vascular access was the permanent arteriovenous fistula (AVF). All the surveyed participants were on haemodialysis modality and 62.5% of them were receiving dialysis three times a week. These data show that hypertension and diabetes are the leading factors toward kidney failure in Oman and the most common co-morbidities exists in the surveyed sub-

population which agree with the data coming from most of the world's countries (e.g. UK and KSA) who reported their kidney failure figures.

Most of the world registries were able to measure the survival of the RRT patient due to having the record of when these patients started the treatment and when they died while they were on treatment. For example, in the UK the survival of kidney failure patients on RRT improved up to 10 years post RRT start for the past 14 years. For Oman RRT population this was never calculated and it is not yet known the survival span of Omani RRT population, but this study revealed that nearly half of the surveyed patients survived on dialysis at least for five years. Prolonged survival is an indicator of the improvement and good management of the patients' care.

Most of the participants had the vascular access recommended by the kidney associations and followed the most common treatment modality across the world, which is in centre-haemodialysis modality. In-centre haemodialysis is the most costly treatments among all RRT, therefore if Oman MOH wants to decrease the expenditure; the ministry has to adopt more kidney transplantation and peritoneal dialysis. Adopting these later treatments will lead to improvements in patients' quality of life, improve the survival span and decrease the cost of RRT care. Also, for how long will the country continue providing a free RRT service for their patients may be it is now the time to delegate part of the service to the private sector in order to provide patients with options of where they prefer to be treated.

The sixth and last research question answered by this project was related to an attempt to identify if there were major psychological and financial impacts on the surveyed sub-population lives. The overall findings reported by most of the participants (84.5% - $n = 288$) in all RDCs of the northern region of Oman showed that dialysis treatment had not caused them stress or worry. Many participants reported that they did not feel they were causing a burden on their family or the community ($n = 283 = 83\%$). The majority reported that they were psychologically stable with few worries or frustrations ($n = 291 = 85.3\%$). Most of the participants reported that dialysis treatment had little financial impact on their lives ($n = 286 = 83.9\%$). However, studying QoL is controversial and beyond the scope of this study and therefore this population needs more in depth studies to understand their perception of their disease and treatments and how health care team can help them improve their quality of life e.g. by recommending adapting psychosocial workers in RDCs who help this population to better adapt and manage their lives.

12 Conclusion

12.1 Contribution of the study

Prior research has shown limited data on Omani treated kidney failure especially with absence of Omani Renal registry. Thus, this research is the first epidemiological study conducted in Oman by an Omani researcher of this depth and size. The results of this study fill a gap in the knowledge about the treated RRT patients in Oman as the information on this subject was limited; it contributes to the knowledge of renal care in the Middle East or developing countries, as well, since Oman is part of these co-operations. This study communicated the evidence of the increasing prevalence of treated RRT patients in Oman through a scientific research using scientific methods and designs. The data generated by this research can contribute to forming an Oman renal registry because this current research provides quantitative data on Oman RRT population since its beginning in 1980 and until 2015 and it also provides data on the characteristics of a cross-sectional sample on dialysis from the northern region of Oman. Otherwise if it is inconvenient for MOH to create Oman Renal registry now, then the Oman MOH can expand the statistics published on the annual MOH report to cover more vital statistics such as incidence and death figures.

The results of this study showed how the Oman RRT services developed from having no renal care provided in the country to having developed and modern RRT services across the country and also it is a free of charge service. Accordingly, for how long Oman MOH can secure funds for this accelerating costly treatment, especially this study indicates that there is a need to increase the current number of RDCs or increasing the number of renal transplantations, which imply the need for further funding. Also, some of the main characteristics of the dialysis sub-population of the northern region of Oman revealed that most of these patients were illiterate and unemployed. The illiteracy is a challenge in improving the patients' compliance with the treatment and therefore it might be helpful to introduce an electronic website or phone apps that contain audio visual materials to educate these patients and also people at risk about how to improve compliance or prevent chronic kidney diseases.

Furthermore, this research contributes to the knowledge such as that there are variations in the treated RRT patients across regions and districts of Oman and this indicates the need for further research to investigate the rational for these variations and so to provide the proper recommendations to overcome the deficiency. Also some more efforts are needed to improve the death register of this population to have more known reported reasons for the deaths in this population as the results from this research showed that many patients under RRT treatments died without known reason recorded. Also, this research can be considered as a base for future research to further explore and study kidney failure in Oman and its population as has been said, the publishing status is limited and also the past research published on renal care of Oman was of questionable quality.

In summary, the major contributions of this study is producing an insight of the epidemiological variables of Oman RRT populations and having an understanding of the major characteristics of a representative sample of one region of Oman, this provided an understanding of the present public health strategies and gives a foundation for the development of future more effective public health strategies for this population. Though the epidemiological variables found by this study concluded that the prevalence and incidence of treated kidney failure in Oman is relatively low but yet the cost is still high and predicted to increase which grab the attention to adapt more effective public health planning particularly at the primary health level. The presentation of this study results helped to raise the awareness of both government and Oman MOH towards the substantial value of prevention, early detection as well as proper management of diabetes mellitus, hypertension and chronic kidney disease. The data presented in this study created a published base for Oman's RRT population, which was not available in this depth and quality. This study signposts the research agenda, especially in Oman, to highlight this topic, enriches the present research knowledge with more updated data through conducting further up-to-date and high quality research studies. This later is very important take home message, all renal care personnel needs to work in collaboration to provide up-to-date information and also published data on this population to help giving deeper insights on the best strategies to improve this population care.

12.2 Limitations of the study

One of the common limitations of this research design is that it identifies only the participants known, for example, it includes the participants on disease registers and misses

people who have the disease but are not yet diagnosed or recorded in the register. This implies that the number of RRT treated patients reported by this research is under reported and so the actual numbers of kidney failure patients are most probably higher in Oman. In general, there are many reasons for under-reporting, for example, the register misses the patients who progress quickly to kidney failure and never visit the hospital for diagnosis or treatment; also, patients who never visit the national medical system and prefer to be diagnosed and treated in the private sector or treated overseas are most likely to be missed; also there are patients who are not followed up after diagnosis with kidney failure so their disease outcomes or the outcome is never known.

Also relying on patient reported data could be one of this study's shortcomings, though this was resolved by counter checking the patient medical records. However, there are some items that relied mostly on patients reported data such as the risk factors existed prior the kidney failure; such as the causes of kidney failure and the impact of kidney failure on participants' lives. The reliability of patients' reported items of this study could be improved if adequate data were found in patient medical records. Well documentation of the patients' medical history since the first visit to the medical agency is essential to integrate a comprehensive picture of patient medical stance. Also, it is of importance to connect all health agencies in a network that show all the patient medical data in a comprehensive profile, especially connecting the primary health institutions records with the other health institutions levels. Also, one of the RDCs was relying on paper-based records and therefore some of the hand-written documents were challenging to read. Also absence of reliable filing system in some of the RDCs led to more time consumptions when looking for some records.

One important limitation was in the survey instrument by using a limited scale of yes or no to measure the QoL of dialysis patients which provided contradictory results to what were reported by most of studies measured the same variable. Focus groups or semi-structured interviews were possible alternatives to measure QoL but thought not applicable at this stage of this research. The reasons for not utilising any one of these strategies to measure QoL are presented in section 6.6.2 page 147.

Another limitation was accessing the participant's participants' medical records with only verbal consent. Although the author ensured that the patients were fully informed it would have been more ethically appropriate if consent was obtained in writing.

Another limitation in general is that similar designs to this research are usually encounter some difficulties in inferring changes over time. This would be true for this study if the data was collected at one point of time and not over a period of time. However, this study attempted to overcome this limitation through gathering data over a year time (the prospective part was from October, 2014 until 31st December 2015 and the retrospective from 1980-2013).

12.3 Implications and recommendations for practice, service delivery and policy

This research provided an initial understanding of epidemiological variations in the pattern of kidney failure in Oman. The results of this research emphasise the awareness of both the Oman government and the health care systems towards the substantial value of prevention, early detection as well as proper management of both chronic kidney disease and diabetes mellitus (hypertension as well) and to develop an active relationship (i.e. partnership) between all care levels, especially the primary care teams in health institutions and in the community, and people at risk of kidney failure. The data produced by this research has created a published database for Oman, which was not previously available to this degree. It can be used to guide the academic nursing, medical, and health-allied disciplines to highlight topics on kidney failure epidemiology with the latest available statistics for their students. This research contributed to the national and international research database, and provided the insight for further research projects based on this research.

The author thinks that this research is considered timely as its conduction responds to the calls that the renal societies are sending across the globe toward increase the knowledge about kidney failure and chronic kidney disease populations across the world, especially the populations of developing countries including Oman.

At all stages, policy-makers need to listen to the evidence provided by qualified research studies and try to modify the existing policies (i.e. public health care policies) to satisfy population needs and global trends. Specifically, the utilisation of research is supported by vision 2050 of Oman MOH (see Health sector in Oman); also the satisfaction of Omani citizens is an ultimate goal of the Oman top leadership. Therefore, it is believed that policy-makers will not reject the formation of a national renal registry. Renal registries have proven their practicality and usability across the world. The time has now come for

the MOH in Oman to upgrade the current kidney failure and RRT register to a renal registry. Creation of a renal registry needs funding, resources and a committed - quality data collection team. It needs people to value data as power and to take the belief that no health system can be upgraded or act efficiently unless they invest in research. This puts a responsibility on all the countries of the world including Oman to gather data about their kidney failure population and make it accessible and available as published material for the patients, the research society, and all concerned public in renal care.

The world is now in a digital era, so it is of urgency to move from the phase of record-keeper (paper-based) to publishers (e-form). Digitalisation of the government's work in Oman is supported by the top leadership; a higher authority of technologies has already been formed in Oman (see Technological Status). This research suggests the development of a nationwide survey utilising the tools in this study, which needs further review and improvements, to gather information about incidence variables and other epidemiological variables of importance, from the time the patient is registered into the system as a chronic kidney disease patient and until the patient is deceased. Renal care in Oman needs an e-form portal (website) hosting all essential information relevant to the people at risk, patients and renal multi-professional teams to share knowledge and sustain professional networking about kidney failure problems. For people who cannot access the website, a renal care campaign can reach them through TV advertisements and social media apps like texting, Whatsapp, Facebook and twitter. It is very important to educate and increase the awareness of the population who are at risk of chronic kidney disease or already have chronic kidney disease in early stages. The fight against chronic disease including chronic kidney disease, diabetes, and hypertension should be undertaken in partnership with all sections of the community, starting with the lay people and ending with the highest leadership in the country. All people in the community should value prevention, as it is the main approach that preserves health and saves lives and saves the economy as well.

Some participants of this research raised concerns on the road distances they travel every week, especially patients coming from District 6. It was suggested that more satellite and nearby dialysis centres were needed to overcome this obstacle, and offer a better chance of treatment compliance for these patients. It is now time to initiate satellite haemodialysis centres, which are community based and closer to patients' homes, and they are managed on a daily basis by renal nurses. The Oman's MOH need to examine the feasibility of home haemodialysis, so it can be offered to patients if found feasible. Also, the Oman's MOH

can offer transportation to their patients and this may be of practical support for some patients who do not have relatives to escort them. All these requirements by patients are linked to the economic capacity of the country and whether the government can increase the budget of Oman's MOH, so the latter can spend more on improving the health services of renal sector. Other option is to shift more patients to use peritoneal dialysis treatment which is more cost-effective, and does not need travelling as it is conducted at home.

The overall findings reported by most of the participants of the cross-sectional study in all RDCs of the northern region of Oman showed, for example, that 84.5% ($n = 288$) of the participants reported that dialysis treatment had not caused them stress or worry. However, this result does not mean to neglect the 15.5% who had worries and stress because of their dialysis treatment impact on their lives. This population might need social workers, who are not incorporated in the current renal multi-disciplinary team in Oman. Renal social workers should be made available for treated kidney failure patients especially the dialysis treatment cohort; they should be available for the patients to provide the social and psychological support the patient's need. These workers can make the patients and their families more aware about all kinds of support offered to them by the Oman's MOH and the government. Patients should find somebody to listen to their problems and complaints. The social workers can be the medium to inform the other renal professionals and renal policy makers about these patients' needs. For example, many participants especially females were not comfortable to undertake their dialysis treatment in a big hall shared with males, which informs the MOH to make separated dialysis halls for each gender.

The Oman's MOH made resources available for kidney transplantation when the program launched in 1988. It is possible to perform kidney transplantation in two major hospitals in Oman which are the Royal Hospital and the Sultan Qaboos University Hospital. And, since 2005 the transplant co-ordination unit and the kidney donor clinic have been running smoothly. Although more than half of the cross-sectional participants wanted to have kidney transplantation (50.7%), but could not find donors. Acceptance of the practice of organ donation needs to be built on within public attitudes to increase the organ donations and reduce the number of patients who might need to wait for years until they get a donor. Kidney transplantation figures need to be increased further in Oman and without increasing the figures of organ donation, this will be impossible to accomplish. What is needed is a campaign on a national and regional level to make people aware of the advantages and risks of organ donation, raising awareness of how it can save many lives. People need to

know that organ donation is a practice approved and supported by Islam. In addition, the experience of KSA in this perspective can be learnt as they have a website published in Arabic language and can be accessed by the public. The website provides significant information on kidney transplantation in KSA. It provided the opinion of Islam on kidney transplantation, which permits organ donation. It allows people to read and understand the policies of kidney transplantation and how they can register themselves as donors within the website itself (<http://www.scot.gov.sa/>). This makes the kidney donation offer accessible and available for Saudi people and the same can be done for Omanis as well.

Finally, the time has arrived to re-activate the national preventive and screening program or initiate a dialogue with the public on all levels, governorates, districts, communities and schools, to increase their awareness on the best ways of modifying their lifestyles to fight kidney diseases. Furthermore, the demographic for this study showed that many patients were likely beyond school age, so strategies to reach this group and similar age groups in the wider community might be incorporated such as reaching them in the community through community-support group, making health education open days and invite them, and reach them through media and phone apps.

12.4 Recommendations for future research

The declaration of Helsinki 1964 set a number of principles for medical research. One of them was to emphasise the importance of ultimately involving human subjects in medical research to ensure medical research progress. Also, the declaration emphasises the importance of “understanding the causes, development and effects of diseases and improving preventive, diagnostic and therapeutic interventions (methods, procedures and treatments) so through these strategies, the patients care standards will ultimately improve. Also, the best proven interventions must be evaluated continually through research for their safety, effectiveness, efficiency, accessibility and quality”.

In relation to what has been said, there are many aspects of kidney disease in Oman that have never been explored or are underexplored. Therefore, there is a space for further research in this field. First, studies on exploring causes of chronic kidney disease in Oman using, perhaps, the triangle of causation to see whether it is agent, environment or host which have caused kidney failure to increase in Oman; also how PESTLE or BEINGS

factors have impact on people at risk and how these factors can be modified to prevent kidney failure incidence. Also, the knowledge produced by this research highlights that diabetes is one of the significant causes of kidney failure in Oman as 47% of the RRT population of Oman in 2009 had diabetic nephropathy leading to kidney failure. Also USRDS (2015) reported that Oman ranked 8th country out of the 57 participant countries of the registry, which had higher percentages of diabetes.

Other studies could be conducted on how chronic kidney disease progresses among Omanis and how it affects the Omani population and who are the people who tend to progress to kidney failure faster and why that is. For example, 'are Omani men more likely than Omani women to report kidney failure?' or 'do Omani men have worse complications and progress faster to death than Omani women following dialysis?', since the evidence from this research says that the incidence of kidney failure is slightly higher among Omani males. Also the death event is higher among the male haemodialysis cohort compared to the female cohort. For example, there were 425 males died in the haemodialysis cohort compared to females (377 female) in 2001-2010. This information will help to examine the differences (RCT design could be used) in the progress towards death in between males and females and therefore develop further understandings to slow this progress and manage the predisposing factors better.

This research revealed some geographical variations in the prevalence of treated kidney failure among the governorates of Oman. For example, the observational cohort study which reported the highest prevalence of dialysis sub-population was in the capital (71.3/100,000) in 2010, and then in 2015, the highest prevalence changed to be in the west end (99/100,000). So why these variations took place and if there were set of factors helped increasing the prevalence in some parts of Oman, how can these factors are reversed to decline the incidence and prevalence. Also, it was noticed that subdivision 2 had less prevalence of dialysis treatment and more educated population so are these two variables (i.e. prevalence and education) linked with positive or negative relationship and if, for example, the relationship was negative then this mean more education should be provided for the public because this will decrease the incidence and then later the prevalence of kidney failure in Oman. Also there were some dips in dialysis treatment in the years 2003, 2005 and 2006, which need to be explored if there were any justification behind this phenomenon and why there is a big difference between the prevalence in the Omani population when compared to the total population? Is it because the high census of non-

Omanis, which helped in changing the figures of treated kidney failure of Oman, if so then further studies needs to be done to confirm or reject this idea. Furthermore, it is recommended that the MOH distinguish the prevalence, when publishing these data, to specify whether individuals belong to the Omani or the total population and also if the dialysis figures are for haemodialysis only or both. The year 2009 showed, higher incidence of dialysis, and of diabetic nephropathy and higher death figures and so further exploration research on this area could be undertaken.

Another study may be needed to evaluate the impact of the current screening program that Oman's MOH is delivering at present. Future studies evaluating the present interventions and treatment for chronic kidney disease and kidney failure patients are needed, to evaluate their effectiveness, usefulness and safety and if they are the best proven interventions. Studies are needed to evaluate the patient on RRT's quality of life, and satisfaction on treatments and care. Also it would be good to explore the effect (short term and long term effects) of less than three dialysis sessions on the Omani dialysis sub-population, as the cross-sectional study found that more than one third (37.5%) of the studied population were undertaking less than three dialysis sessions per a week.

More epidemiological studies are needed to identify the specific determinants of the epidemiological changes found by this research. It is good to study different aspects of the dialysis sub-population especially infections, hospitalisation, survival, causes of death and others to develop further understanding of this population and thereafter recommend the best way to improve their care and their quality of life. Also, the paediatric population needs some research studies conducted on them, and also to explore the experience of their parents in dealing with a kidney failure child. The cost given by this study was for the direct costs for dialysis sessions, so it would be good to conduct future a study to explore and calculate the direct and the indirect expenses of dialysis and kidney transplantation in Oman. All this information will add to the body of knowledge and will help for better understanding of the real situation of treated kidney failure in Oman and also predict the future and modify health strategies and plans accordingly.

12.5 Summary

Local and national initiatives in Oman will face a hard job in fighting chronic kidney disease, because it is too difficult to change people's unhealthy habits in a short time, however, it is worthwhile to undertake such initiatives. The people of Oman need a lot of assistance to make them aware about the healthier choices available for them. However, to change the kidney failure trajectory in Oman, the Oman's MOH needs to work harder on all levels to address the increasing burden of risk factors leading to kidney failure such as diabetes, hypertension, and obesity. Also, the care of the Oman's RRT population is complex and needs a multi-professional team to help this population optimise their quality of life. Nowadays, renal nurses are taking the lead in managing the dialysis patients' care. Accordingly, renal nurses have to provide the dialysis support that patients need; allow patients to express their needs and help in satisfying them; renal nurses are the main advocates for this sub-population, so they have to encourage decision-making, care-reviewing and share the latest best evidences of good care with the renal care multi-professional team in order to achieve the best holistic care. Also, renal care remains a multi-disciplinary care and all health professionals involved need to contribute in improving these population health outcomes.

Finally and to summarise, this research addresses the lack of research evidence on the epidemiology of kidney failure population of Oman. Accordingly, this research was conducted to communicate the evidence available on the epidemiology of treated kidney failure in Oman and the characteristics of a representative sub-population, which was the dialysis cohort of the northern region of Oman. The evidence presented by this research showed part of the picture and not yet the full picture on the status of kidney failure in Oman. Conducting the recommended research as outlined earlier will help to complete the picture of the kidney failure of Oman. The complete picture will provide the renal carers and renal care concerned with the necessary knowledge on strengths and weaknesses of existing health plans and of different treatments so they can alter existing plans and ultimately improve these population health outcomes. These improved population health outcomes (i.e. renal health outcomes) can be achieved if working on five pillars as this research concluded. First pillar is to work on national prevention programme to orient the population on the best health practices that can protect them from non-communicable disease such as diabetes. Second pillar is to activate the current detection and screening programme for NCDs, it should be packed with thorough documentation and referral

system. Third pillar is to design an education and awareness program to improve the public knowledge about organ donation. Fourth pillar is to initiate the Oman Renal Registry aiming to improve the volume and quality of renal data about Oman. Fifth pillar is to fund and guide the renal research to widening the knowledge base of renal disease about Oman.

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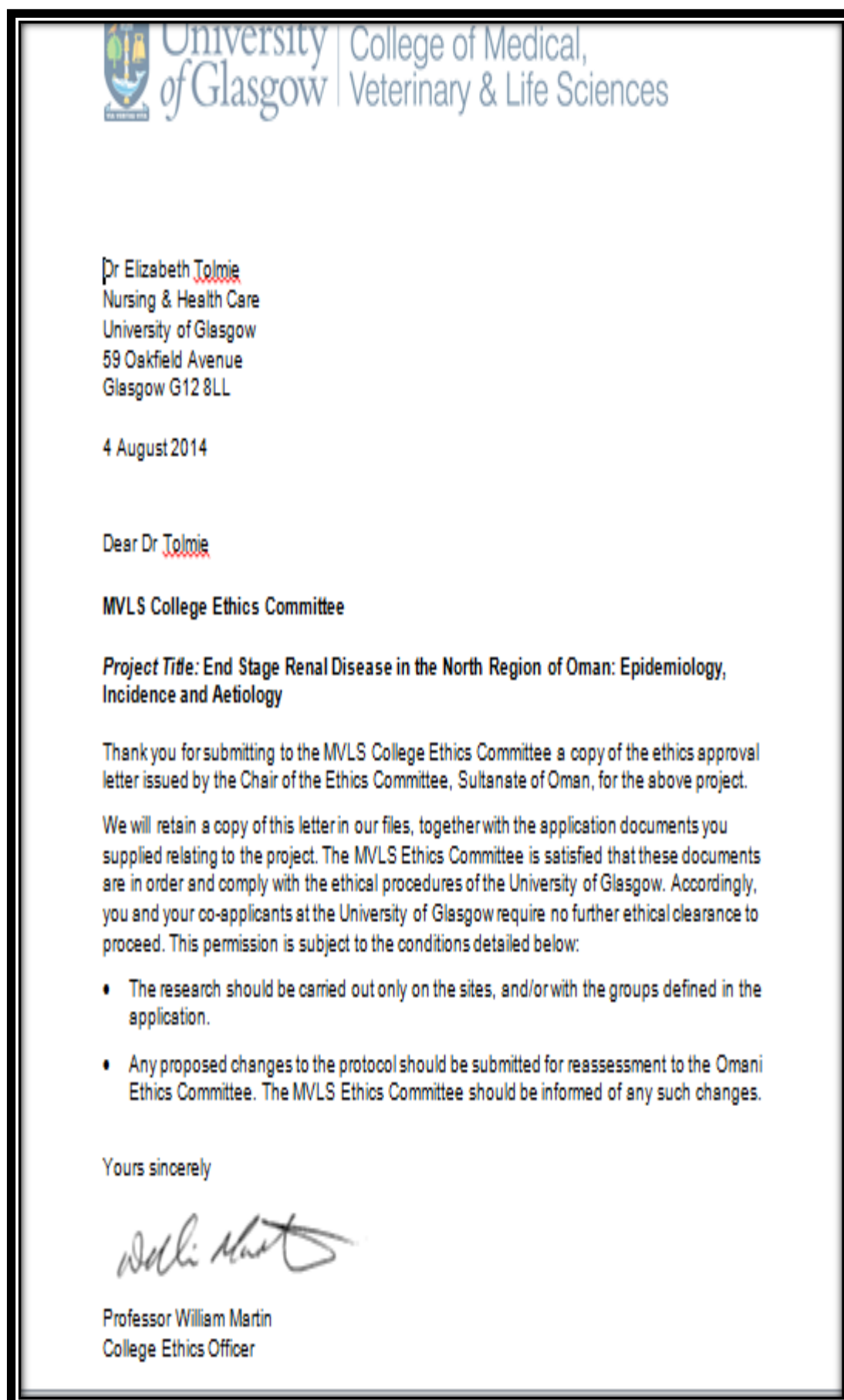
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Appendices




Appendix A – Ethics' forms

A-1 (The 1st ethical approval letter from MOH of Oman)

<p><i>Sultanate of Oman</i> <i>Ministry of Health</i> <i>Directorate General of Planning</i></p>		<p>سلطنة عُمان وزارة الصحة المديرية العامة للتخطيط</p>
<p>Ref. MH/DGP/R&S/PROPOSAL_ APPROVED/17/2014</p>	<p>الرقم:</p>	
<p>Date. 22.07.2014</p>	<p>التاريخ:</p>	
<p>الموافق:</p>		
<p>_____ Mrs. Ruqiya Khamis Abdullah Al-Za'abi</p>		
<p>Principal Investigator</p>		
<p>Study Title: "End-Stage Renal Disease in North Region of Oman: Epidemiology, Incidence and aetiology"</p>		
<p>After compliments</p>		
<p>We are pleased to inform you that your research proposal "End-Stage Renal Disease in North Region of Oman: Epidemiology, Incidence and aetiology" has been approved by Research and Ethical Review and Approve Committee, Ministry of Health.</p>		
<p>Regards,</p>		

A-2 (The ethical approval letter from University of Glasgow)

A-3 (The 2nd ethical approval letter from MOH of Oman)

<p>Sultanate of Oman Ministry of Health Directorate General of Planning and Studies</p>		<p>سلطنة عُمان وزارة الصحة المركزية العامة للتخطيط والدراسات</p>
<p>Ref. : MOH/DGP/2014/ 918</p>	<p>الرقم :</p>	
<p>Date : October 12, 2014</p>	<p>التاريخ :</p>	
<p>.....</p>	<p>الموافق :</p>	
<p>Dr. Elizabeth Tolmie Nursing & Health Care University of Glasgow</p>		
<p>Dear Dr. Elizabeth</p>		
<p><u>Sub: End Stage Renal Disease in the North Region of Oman: Epidemiology, Incidence & Aetiology (Version 2)</u></p>		
<p>We would like to inform that the Research & Ethical Review committee from Ministry of health has already approved the study and the copy of the approval letter has been forwarded to your office. A copy of the same is enclosed for your kind reference.</p>		
<p>Any clarification from your side could be communicated directly with the Principal Investigator Mrs. Ruqiya Khamis Abdullah Al Zaabi, who is authorized to conduct the study as per the approval letter.</p>		
<p>Thanking you and with Best regards,</p>		
		

A- 4 (The research proposal's part that address obtaining the data from the patient medical profile)

interview will be guided by a 'data collection form' designed by the P.I. (Please see Appendix 5.6). First, the study 'information sheet' will be handed to the patients and explained. Then, the participant and the researcher will sign the informed consent at the same time. At this stage the patient's name will be coded using names list sheet where all the patients' names will be maintained confidentially with their codes. The match code of the patient will be labeled to the 'data collection form' prior starting. Then, the patient will be interviewed for 20-45minutes. Following that, the data gathered will be cross checked using the patient profile. And finally the data will be cross checked with the assigned health care giver to validate that the attained information is correct. The patients will have the full authority to accept or reject the participation in the study. The patients will be approached during their dialysis sessions in the RDC. All the patients in the register will be recruited by conducting a short conversation with them explaining the research topic, the patients' roles and giving them the option to participate. For this purpose, the P.I. will attend the RDCs on the daily basis until she covers all the patients on weekly-regular dialysis at the target-RDC. The patients may wish to participate on any day where he/she will be on dialysis session and it is up to them to consider when the good time of the day for them to be

Sampling technique of Phase TWO Study:

Non-probability-convenience sampling

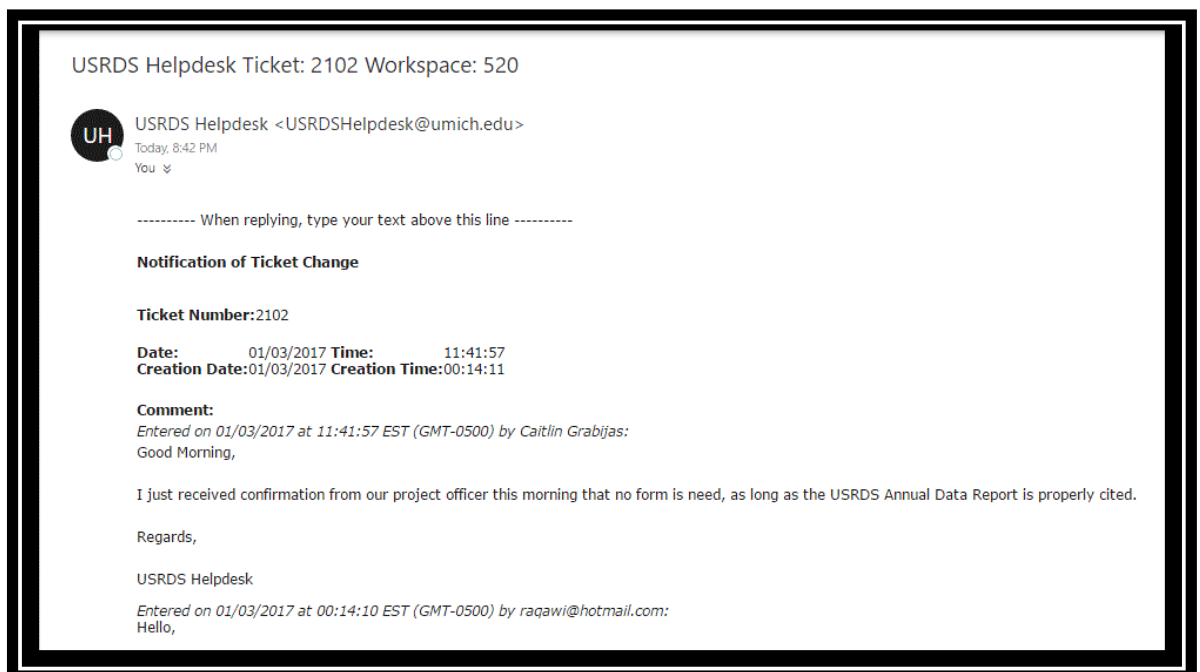
Survey every patient having ESRD patients in the North of Oman ([REDACTED]). The patients will be identified by using the four RDC's registers of all patients undergoing dialysis at the four-targeted

Appendix B – Copy right permissions

B-1 (Copy right permission, Scottish Renal Registry)



B-2 (USRDS permission)



B-3 (UKRR permission)

Stephanie Shearn <Stephanie.Shearn@renalregistry.nhs.uk>

Tue 1/3, 2:11 PM

You; Renal Registry (renalregistry@renalregistry.nhs.uk) ✉

Dear Ruqiya,

You are permitted to use the figure however please use the correct citation listed on our website.

Kind regards

Stephanie Shearn

Finance Officer

UK Renal Registry

Please note my normal working hours are 10:00-14:15 Monday to Friday.

T 0117 4148150

F 0117 4148171

<http://www.renalreg.org>

UK Renal Registry | Learning and Research Building | Southmead Road | Bristol | BS10 5NB




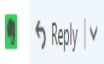
The Renal Registry is part of the Renal Association

Registered office: Durford Mill, Petersfield, Hampshire GU31 5AZ

Registered company No 2229663.

B-4 (RAND copy right permission)

Auto Reply RAND Health Inquiries

 Maples, Ingrid <imaples@rand.org> 
Today, 1:50 PM
You ▾

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B-5 (Dr. Omar Abboud e-mail)

Your article: Incidence, Prevalence, and Treatment of ESRD in The Middle East, 2006 



omar abboud <oiabboud@yahoo.com>

Sat 15/02/2014, 10:04

Ruqiya Khamis Abdullah Ali Al Za'abi 



RESEARCH mail

Dear Dr Ruqiya

Thank you for the message.

You are absolutely correct that my article does not mention information about the prevalence rate of ESRD in Oman.

Actually information is very little about nephrology in the ME region. As I mentioned in the article additional information was obtained from conferences, symposia and direct communications; publications are limited. I did not find publications from Oman.



I will look for other articles related to the subject and send them to you.

Kind regards

Omar Abboud

.....

Appendix C – (The letter of peritoneal dialysis cost from MOH of Oman)

Directorate General of Medical Supplies	المديرية العامة للتأمين الطبي مسقط
Muscat	
MH/DGMS/DSS/S/ 6274	
22-10-1435H	
19-8-2014	
DR. AHMED AL BUSAIDI DIRECTOR OF COMMUNICABLE DISEASE SURVEILLANCE & CONTROL DGHA, MINISTRY OF HEALTH	
After Compliments,	
<u>Re: PERITONEAL DIALYSIS</u>	
We refer to your letter no. MH/DGHA/DSDC/NCD/193/14 DT. 20.07.2014 on the above subject.	
We currently have 111 patients on an average cost per treatment of RO 25 000 per patient per year (25 x 365= 9125). For existing patients we need RO 1,012,875/- and an additional increase of RO 912,500 on an annual basis for 100 new patients every year.	
This has been already informed to Ministry Of Finance for allocation of budget (RO 2,007,500/- for 2015 alone) through our Arabic letter No. MH/DGMS/MMA/4/H/76/762 DT. 09.07.2014. (copy attached)	
Yours truly,	
	
(Ph. ANISA RASOOL) DIRECTOR OF SPECNS. & SUPPLIES	
Encl: as above	
Cc: DIRECTOR GENERAL	

Appendix D - Data collection forms

D-1 (Information sheet given to patients in Arabic)

ورقة المعلومات الخاصة بالمشاركين
دعوة: أنتم مدعوون للمشاركة في هذه الدراسة البحثية
عنوان الدراسة:
دراسة انتشار ومعدل حدوث وأسباب مرض الفشل الكلوي في منطقة شمال عمان
(تقرأ وتشرح للمشارك أو من يقوم بمقامه في أثناء المقابلة الشخصية أو الهاتفية)

قبل أن تقرر، من المهم لك أن تفهم لماذا يجري البحث وما هو عرض الدراسة وما سنطوى عليه يرجى أخذ/أعطاء الوقت الكافي لقراءة وفهم المعلومات التالية:

هدف الدراسة: عمل أول دراسة لانتشار ومعدل حدوث وأسباب مرض الفشل الكلوي في منطقة شمال عمان.

أسباب اختيارك: هو أنك مطابق للمعايير المحددة في معايير الإلتحاق لهذه الدراسة ؛ فإنت مريض تم تشخيصك بمرض الفشل الكلوي؛ وإنت على الضمك الكلوي الإسبوعي ؛ وإنت على الضمك لفترة لا تقل عن ثلاثة اشهر على الأقل؛ وإنت مسجل كمريض ضمك كلوي في واحدة من مراكز الضمك الكلوي في شمال عمان.

هل يجب إن اشرك: الأمر متروك لك لإتخاذ قرار المشاركة من عدمه ؛ إذا قررت المشاركة فسوف تبقى هذه الورقة معك؛ وسوف يطلب منك التوقيع على استمارة الموافقة في المشاركة، وفي كل الأحوال أنت لا تزال حر في الانسحاب في أي وقت، وبدون إعطاء أي مبرر.

مذا سيحدث لي إذا قررت المشاركة: إذا كنت سعيدا في المشاركة فسوف يتم إجراء مقابلة معك أثناء حضورك لمركز الضمك الكلوي الخاص بك، وقد تستغرق حوالي 20-45 دقيقة من وقتك ؛ ولك الحرية في إيقاف المقابلة أو أخذ استراحة في أي وقت إذا كنت تشعر بسوء. سيتم استخدام البيانات لغرض البحث العلمي فقط.

ما هي العيوب والمخاطر المحتملة للمشاركة: لا توجد عيوب معروفة أو مخاطر للمشاركة في هذه الدراسة، على الرغم من ذلك إذا واجهت أي لصلص بالتحب أو الضيق أو الإزعاج أثناء المقابلة فيمكنك إيقاف المقابلة.

ما هي الفوائد المحتملة للمشاركة: قد لا تتلقى فائدة مباشرة من المشاركة في هذه الدراسة ولكن المعلومات التي سيتم جمعها من خلال هذه الدراسة ستتيح لنا فهم أفضل لتوجهات وحالة ومسببات مرض الفشل الكلوي في شمال عمان.

هل مشاركتي في هذه الدراسة ستظل سرية: نعم جميع المعلومات التي سيتم جمعها عنك أثناء البحث سوف يتم الحفاظ على سريتها التامة

مذا سيحدث لنتائج الدراسة : سيتم نشر نتائج البحث بمجرد الإلتهاء من الدراسة البحثية والذي قد يكون سنتين من الآن وذلك بمجرد أخذ الموافقات اللازمة لذلك.

من هو المنظم والممول لهذا البحث: هذا البحث مشروع رسالة دكتوراه ممول من وزارة التعليم العالي.

من الذين قاموا بمراجعته هذه الدراسة: أعضاء هيئة التدريس في جامعة جلانكوفي المملكة المتحدة ولجنة الأخلاقيات في وزارة الصحة في سلطنة عمان.

أود أن أشرككم كثيرا على المشاركة من هذه الدراسة
 جهة الإتصال للحصول على مزيد من المعلومات:
 رقية خميس الزعالي

D-2 (Information sheet in English)

Participant Information Sheet

NOTE: (to be handed over, explained or read for the patient or authorized person prior the interview or the telephone call)

Study Title:

End-Stage Renal Disease in North Region of Oman: Epidemiology, Incidence and Aetiology

Invitation: *'You are being invited to take part in a research study. Before you decide, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully.'*

'Thank you for reading this.'

The purpose of the study:

To develop the first description of the epidemiology and characteristics of dialysis-treated ESRD in the North Region of Oman

Reasons for choosing the candidate: (Why have I been chosen?)

The reason for choosing you is that you match the criteria specified in the inclusion criteria of this study which are; you are a patient who is diagnosed to have ESRD (any age); you are on regular-weekly dialysis for a minimum period of at least three months; and you are registered as a dialysis-patient in one of the four Renal dialysis centers/units in the North Region of Oman.

Do I have to take part?

'It is up to you to decide whether or not to take part. If you decide to take part you will be given this information sheet to keep and you will be asked to sign a consent form. If you decide to take part, you are still free to withdraw at any time and without giving a reason'.

What will happen to me if I take part?

If you are happy to take part in the study you will be asked to be interviewed. The interview should take around 20-45 minutes of your time. The interview will take place while you are doing your dialysis session and you are free to stop the interview at any time if you feel ill or you wish to have a break. The data collected will be used for research which is planned to be published in two years' time. At all stages of this research your contribution will be anonymous. It will not be possible to identify you from your answers to the questions or from your disease profile.

What are the possible disadvantages and risks of taking part?

There are no known disadvantages or risks in taking part in this study, although you may experience tiredness, distress or inconvenience during the interview. So if you are unhappy at any point of the interview, then you can stop the interview.

What are the possible benefits of taking part?

'You may not receive a direct benefit from taking part in this study. The information that is collected during this study will give us a better understanding of the trends and status of ESRD in the north of Oman.

Will my taking part in this study be kept confidential?

'All the information, which is collected, about you during the course of the research will be kept strictly confidential. You will be identified by a code saved in a secure place with the researcher. All the data belonging to you will be labeled using that code only.

What will happen to the results of the research study?

The research study will be finalized in two years' time from now. Once it is approved the research results will be published.

Who is organising and funding the research?

The research is a PhD project. The funding of this research is originally afforded by Ministry of Higher Education.

Who has reviewed the study?

The research project has been reviewed by the Research Committee in MoH in Oman and by the Faculty of Medicine Ethics Committee in the University of Glasgow.

Contact for further information:


Ruqiyah Khamis Al-Za'abi

Phone No.: +968 92265051

E-mail address: raqawi@hotmail.com

I would like to thank you very much for taking part in this study.

D-3 (Informed consent given to patients in Arabic)

	University of Glasgow	
نموذج أقرار بالموافقة		
الرقم التعريفي الخاص بالمريض: _____		
عنوان الدراسة: <u>دراسة أنتشار ومعدل حدوث وأسباب مرض الفشل الكلوي في منطقة شمال عمان</u>		
اسم الباحث الرئيسي: رقية الزعابية		
جهة البحث : جامعة جلاسكو، كلية الطب والطب البيطري و علوم الحياة، كلية التمريض		
<u>الرجاء وضع توقيعك أو بصمتك في آخر الصفحة</u>		
1. أؤكد أنني قرأت، وفهمت ورقة المعلومات الخاصة بهذه الدراسة وكان لدى فرصة لطرح الأسئلة		
2. أؤكد أنه قد شرح لي الإجراءات العامة المتعلقة بسرية المعلومات وعدم الكشف عن هويتي في أطروحة الدراسة		
3. أفهم أنني أستطيع الانسحاب من الدراسة في أي وقت		
4. أوافق طوعاً على المشاركة في هذه الدراسة		
5. أفهم أن نتائج هذه الدراسة سوف تشكل جزءاً من أطروحة دكتوراه		
اسم المشارك أو المحول عنه: التاريخ التوقيع أو البصمة		
أسم الباحث: رقية حميس الزعابية التاريخ التوقيع		

D-4 (Informed consent in English)



University
of Glasgow

5.3-Informed Consent of Research Participant (Form 5.3)

Interview Consent Form

Identification Number (code): _____

Study Title: Research title: End-Stage Renal Disease in North Region of Oman: Epidemiology, Incidence and Aetiology

Name of P.I: Mrs. Ruqiya Al-Za'abi

Dept. /Program: Nursing & Health Care School, College of Medical, Veterinary & Life Sciences, University of Glasgow

Please put your signature at the end only

1. I confirm that I have read and understand the Participant Information sheet for the above study and I have had the opportunity to ask questions
2. Procedures for confidentiality and anonymity of data have been explained to me
3. I understand that I can withdraw from the study at any time
4. I voluntarily agree to participate in the study
5. I understand that the results of this study will form part of a PhD thesis

Name of Participant or authorized Date Signature or stamp

Researcher Date Signature

*1 copy for participant or authorized person and 1 copy for researcher

D-5 (The survey 1st version used in the pilot study)

Data collection Form:
Kidney Dialysis patient Survey

1. Date of the data collection:

2. Name of the RDC you are collecting the data in:

<input type="checkbox"/> 1 Sohar Hosp.	<input type="checkbox"/> 3 BUSTAQ
<input type="checkbox"/> 2 Sohar EHC.	<input type="checkbox"/> 4 Musanaah

Patient's Demographics:

3. Place of residence:

<input type="checkbox"/> 1 Sohar	<input type="checkbox"/> 2 Sabara
<input type="checkbox"/> 3 Shinas	<input type="checkbox"/> 4 Liwa
<input type="checkbox"/> 5 Al-Khabourah	<input type="checkbox"/> 6 Ar-rustaq
<input type="checkbox"/> 7 Nakhal	<input type="checkbox"/> 8 Wadi Almarwil
<input type="checkbox"/> 9 AL-Awaabi	<input type="checkbox"/> 10 Suwaiq
<input type="checkbox"/> 11 AL-Musanaah	<input type="checkbox"/> 12 Barka
<input type="checkbox"/> 13 Others	<input type="checkbox"/> 14 Not answered

4. Parent dialysis unit:

<input type="checkbox"/> 1 Baushar	<input type="checkbox"/> 2 Royal Hosp.
<input type="checkbox"/> 3 Quriyat	<input type="checkbox"/> 4 Sohar Hosp.
<input type="checkbox"/> 5 Sohar EHC.	<input type="checkbox"/> 6 BUSTAQ
<input type="checkbox"/> 7 Musanaah	<input type="checkbox"/> 8 Al-Buraimi
<input type="checkbox"/> 9 Nizwa	<input type="checkbox"/> 10 Sumail
<input type="checkbox"/> 11 S.Q.H.	<input type="checkbox"/> 12 Ibrj Hosp.
<input type="checkbox"/> 13 Sur Hos.	<input type="checkbox"/> 14 Sinaw
<input type="checkbox"/> 15 Jaalan RBA	<input type="checkbox"/> 16 Ibra Hosp.
<input type="checkbox"/> 17 Khasah	<input type="checkbox"/> 18 Dibba
<input type="checkbox"/> 19 Others	<input type="checkbox"/> 20 Not answered

5. Date of Birth: 1

Or age: 0-17 2 18-45 3 46-64 4 65-75 5 ≥75 6

Don't Know 7 Not answered 8

6. Gender: Male 1 Female 2

Don't Know 3 Not Answered 4

7. Ethnicity or Race:

White <input type="checkbox"/> 1	Indo-Asian <input type="checkbox"/> 2
Black <input type="checkbox"/> 3	Mixed <input type="checkbox"/> 4
Others <input type="checkbox"/> 5	Don't Know <input type="checkbox"/> 6
	Not Answered <input type="checkbox"/> 7

8. Education level:

Illiterate <input type="checkbox"/> 1	Read & write only <input type="checkbox"/> 2
Primary (1-9) <input type="checkbox"/> 3	Secondary (10-12) <input type="checkbox"/> 4
College <input type="checkbox"/> 5	Post college <input type="checkbox"/> 6
Don't Know <input type="checkbox"/> 7	Not answered <input type="checkbox"/> 8

9. Occupation:

YES <input type="checkbox"/> 1	NO <input type="checkbox"/> 2
Intermittent <input type="checkbox"/> 3	Not answered <input type="checkbox"/> 4

9A. If you have NO occupation, is it because of you having ESRD?

YES <input type="checkbox"/> 1	NO <input type="checkbox"/> 2
Not sure <input type="checkbox"/> 3	Not answered <input type="checkbox"/> 4

9B. If you have NO occupation because of the impact of ESRD on your life, then can you remember after how many years of you diagnosed with ESRD, you left your occupation?

- | | | | |
|-------------|--------------------------------|-------------|--------------------------------|
| 0-5 years | <input type="text" value="1"/> | 6-10 years | <input type="text" value="2"/> |
| 11-15 years | <input type="text" value="3"/> | 16-20 years | <input type="text" value="4"/> |

Or specific date of you leaving your occupation

10. Are you living?

- | | | | |
|--------------|--------------------------------|--------------|--------------------------------|
| Alone | <input type="text" value="1"/> | With family | <input type="text" value="2"/> |
| With friends | <input type="text" value="3"/> | NO Where | <input type="text" value="4"/> |
| Others | <input type="text" value="5"/> | Not Answered | <input type="text" value="6"/> |

11. Are you living in?

- | | | | |
|------------|--------------------------------|--------------|--------------------------------|
| Urban city | <input type="text" value="1"/> | Rural area | <input type="text" value="2"/> |
| Mixed | <input type="text" value="3"/> | Not Answered | <input type="text" value="4"/> |

Disease Profile:

12. Primary diagnosis:

- | | | | |
|--------------|--------------------------------|--------------------|--------------------------------|
| Diabetes T1 | <input type="text" value="1"/> | Diabetes T2 | <input type="text" value="2"/> |
| Genetic | <input type="text" value="3"/> | Glomerulonephritis | <input type="text" value="4"/> |
| Urological | <input type="text" value="5"/> | Hypertension | <input type="text" value="6"/> |
| Others | <input type="text" value="7"/> | Don't know | <input type="text" value="8"/> |
| Not Answered | <input type="text" value="6"/> | | |

13. What are the markers used to diagnose you as you had ESRD?

- | | | | |
|---------------|--------------------------------|-----------------------|--------------------------------|
| Blood Test | <input type="text" value="1"/> | Urine Test | <input type="text" value="2"/> |
| eGFR | <input type="text" value="3"/> | Imaging Tests | <input type="text" value="4"/> |
| Kidney biopsy | <input type="text" value="5"/> | Nephrologists Opinion | <input type="text" value="6"/> |
| Others | <input type="text" value="7"/> | Don't know | <input type="text" value="8"/> |
| Not answered | <input type="text" value="8"/> | | |

14. Co-morbidities:

- | | | | |
|----------------|--------------------------------|------------------|--------------------------------|
| Not reported | <input type="text" value="1"/> | Hypertension | <input type="text" value="2"/> |
| Diabetes T1 | <input type="text" value="3"/> | Diabetes T2 | <input type="text" value="4"/> |
| Cardiovascular | <input type="text" value="5"/> | Vascular disease | <input type="text" value="6"/> |
| Others | <input type="text" value="7"/> | Not answered | <input type="text" value="8"/> |

15. Date of 1st diagnosis with ESRD

- | | | | |
|-------------|--------------------------------|-------------------|--------------------------------|
| 0-5 years | <input type="text" value="2"/> | 6-10 years | <input type="text" value="3"/> |
| 11-15 years | <input type="text" value="4"/> | 16-20 years | <input type="text" value="5"/> |
| | | 21 years and more | <input type="text" value="6"/> |
| Don't Know | <input type="text" value="7"/> | Not answered | <input type="text" value="8"/> |

16. Did you start dialysis?

- | | |
|--------------------------------------|--------------------------------|
| Immediately after diagnosis (0-3m) | <input type="text" value="1"/> |
| Long time after (More than 3 months) | <input type="text" value="2"/> |
| Don't Know | <input type="text" value="3"/> |
| Not Answered | <input type="text" value="4"/> |

17. Date of 1st dialysis

- Or:
- | | | | |
|-------------|--------------------------------|-------------------|--------------------------------|
| 0-5 years | <input type="text" value="2"/> | 6-10 years | <input type="text" value="3"/> |
| 11-15 years | <input type="text" value="4"/> | 16-20 years | <input type="text" value="5"/> |
| | | 21 years and more | <input type="text" value="6"/> |
| Don't Know | <input type="text" value="7"/> | Not Answered | <input type="text" value="8"/> |

18. Treatment modality:

- | | | | |
|------------|--------------------------------|--------------|--------------------------------|
| HD | <input type="text" value="1"/> | HDF | <input type="text" value="2"/> |
| PD | <input type="text" value="3"/> | Mixed | <input type="text" value="4"/> |
| Don't Know | <input type="text" value="5"/> | Not answered | <input type="text" value="6"/> |

19. Number of dialysis sessions per week:

- | | | | |
|------------|--------------------------------|--------------|--------------------------------|
| One | <input type="text" value="1"/> | Two | <input type="text" value="2"/> |
| Three | <input type="text" value="3"/> | Varied | <input type="text" value="4"/> |
| Don't Know | <input type="text" value="5"/> | Not answered | <input type="text" value="6"/> |

20. Total hours of dialysis per week:

- 1-3 hours 1 4-6 hours 2
 7-9 hours 3 >10 hours 4
 Don't Know 5 Not Answered 6

21. What time of day do you START your dialysis treatments?

- AM 1 PM 2
 Varied 3
 Don't Know 4 Not Answered 5

22. Type of vascular access:

- Fistula 1 Catheter 2
 Others 3
 Don't Know 4 Not Answered 5

23. Transferred from other RDC in the Previous years:

- YES 1 NO 2
 Don't Know 3 Not Answered 4

23A. If yes when transferred 1

- Or:
 0-5 years 2 6-10 years 3
 11-15 years 4 16-20 years 5
 Don't Know 6 Not Answered 7

24. Registered on transplantation waiting list:

- YES 1 NO 2
 Don't Know 3 Not Answered 4

25. Had you ever did renal transplantation?

- YES 1 NO 2

25A. Had your renal transplantation failed?

- YES 1 NO 2
 Don't Know 3 Not Answered 4

25B. Your renal transplantation failed after how many years? 1

- Or: 0-5 years 2 6-10 years 3
 11-15 years 4 16-20 years 5
 Don't Know 6 Not Answered 4

Risk factor at incidence:

26. Proteinuria:

- YES 1 NO 2
 Don't Know 3 Not Answered 4

27. Hypertension:

- YES 1 NO 2
 Don't Know 3 Not Answered 4

28. Family history of ESRD:

- YES 1 NO 2
 Don't Know 3 Not Answered 4

29. High dietary protein intake:

- YES 1 NO 2
 Don't Know 3 Not Answered 4

30. Low socio-economic status:

- YES 1 NO 2
 Don't Know 3 Not Answered 4

31. Obesity:

- YES 1 NO 2
 Don't Know 3 Not Answered 4

32. Diabetes:

YES 1 NO 2Don't Know 3 Not Answered 4

33. Anaemia:

YES 1 NO 2Don't Know 3 Not Answered 4

34. Dyslipidaemia:

YES 1 NO 2Don't Know 3 Not Answered 4

35. Nephrotoxins (NSAIDs, antibiotics, radiological contrast, light chains):

YES 1 NO 2Don't Know 3 Not Answered 4

36. Smoking

YES 1 NO 2Don't Know 3 Not Answered 4

37. Primary renal disease

YES 1 NO 2Don't Know 3 Not Answered 4

38. Cardiovascular disease

YES 1 NO 2Don't Know 3 Not Answered 4

39. Urological disorders (obstruction, recurrent urinary infections):

YES 1 NO 2Don't Know 3 Not Answered 4

40. Limited access for RRT service

YES 1 NO 2

41. Environmental factors (e.g. weather):

YES 1 NO 2Don't Know 3 Not Answered 4

42. Sedentary lifestyle

YES 1 NO 2Don't Know 3 Not Answered 4

43. Health care believes

YES 1 NO 2Don't Know 3 Not Answered 4

44. Cultural factors such as delayed presentation and acceptance of RRT:

YES 1 NO 2Don't Know 3 Not Answered 4

45. Late diagnoses:

YES 1 NO 2Don't Know 3 Not Answered 4

46. Late referral:

YES 1 NO 2Don't Know 3 Not Answered 4Impact of ESRD and RRT on patients:

47. My kidney disease interferes too much with my life:

YES 1 NO 2Don't Know 3 Not Answered 4

48. I feel like a burden on my family and on the community:

YES 1 NO 2

49. I feel frustrated dealing with my kidney disease:

YES 1 NO 2

Don't Know 3 Not Answered 4

50. I do not have sufficient income because of my ESRD and RRT treatments:

YES 1 NO 2

Don't Know 3 Not Answered 4

51. It takes me long after dialysis to recover and be able to do my usual activities:

YES 1 NO 2

Don't Know 3 Not Answered 4

52. I have many worries because of my kidney failure and dialysis treatment:

YES 1 NO 2

Don't Know 3 Not Answered 4

53. What do you think is the cause of your renal failure?

1

Don't Know 3 Not Answered 4

Death Profile:

54. Date of death:.....

55. Reason for death:.....

56. Age on death:.....

End of the Questionnaire.

D-6 (The revised final survey)

Kidney Dialysis patient's Survey					
Date of the data collection:		<input type="text" value="/ /"/>		(Day / Month / Year)	
Patient's Demographics:					
1.	Place of residence:	<input type="checkbox"/> 1. Sohar	<input type="checkbox"/> 2. Saham	<input type="checkbox"/> 3. Shinas	
		<input type="checkbox"/> 4. Liwa	<input type="checkbox"/> 5. Al Khabura	<input type="checkbox"/> 6. As Suwaiq	
		<input type="checkbox"/> 7. Nakhal	<input type="checkbox"/> 8. Wadi Al Maawil	<input type="checkbox"/> 9. Al Rustaq	
		<input type="checkbox"/> 10. Al Awaabi	<input type="checkbox"/> 11. Al Musanaah	<input type="checkbox"/> 12. Barka	
		<input type="checkbox"/> 13. Other	Specify Other:		
2.	Parent dialysis unit:	<input type="checkbox"/> 1. Baushar	<input type="checkbox"/> 2. Royal Hosp.	<input type="checkbox"/> 3. Quriyaat	
		<input type="checkbox"/> 4. Sohar Hosp.	<input type="checkbox"/> 5. Sohar EHC.	<input type="checkbox"/> 6. Rustaq	
		<input type="checkbox"/> 7. Musanaah	<input type="checkbox"/> 8. Al-Buraimi	<input type="checkbox"/> 9. Nizwa	
		<input type="checkbox"/> 10. Sumail	<input type="checkbox"/> 11. S.Q.H.	<input type="checkbox"/> 12. Ibra Hosp	
		<input type="checkbox"/> 13. Sur Hos.	<input type="checkbox"/> 14. Sinaw	<input type="checkbox"/> 15. Jaalan BBA	
		<input type="checkbox"/> 16. Ibra Hosp	<input type="checkbox"/> 17. Khasab	<input type="checkbox"/> 18. Dibba	
		<input type="checkbox"/> 19. Other	Specify Other:		
3.	Name of the RDC, dialysis unit: the participant is dialysing in at present:				
		<input type="checkbox"/> 1. Sohar Hosp.	<input type="checkbox"/> 2. Sohar EHC.	<input type="checkbox"/> 3. Rustaq	
		<input type="checkbox"/> 4. Musanaah.	Specify Other:		
4.	Date of Birth:	<input checkbox"="" type="text" value="... / ... /</td> <td>(Day / Month / Year)</td> </tr> <tr> <td>5.</td> <td>Gender:</td> <td><input type="/> 1. Male		<input type="checkbox"/> 2. Female	
6.	Nationality:	<input type="checkbox"/> 1. Omani	<input type="checkbox"/> 2. Non-Omani		
7.	Ethnicity or Race:	<input type="checkbox"/> 1. White	<input type="checkbox"/> 2. Black	<input type="checkbox"/> 3. Asian	
		<input type="checkbox"/> 4. Other		Specify Other:	
8.	Marital Status: (If the answer is 'divorced' then go to the next question and if the answer is the other three then go to question number 10):				
		<input type="checkbox"/> 1. Single	<input type="checkbox"/> 2. Married	<input type="checkbox"/> 3. Divorced	
		<input type="checkbox"/> 4. Widowed			
9.	If you are Divorced, is it because of your sickness with ESRD and being on dialysis:			<input type="checkbox"/> Yes <input type="checkbox"/> No	
10.	Education level:	<input type="checkbox"/> 1. Illiterate	<input type="checkbox"/> 2. Read & Write	<input type="checkbox"/> 3. Primary (1-9)	
		<input type="checkbox"/> 4. Secondary (10-12)	<input type="checkbox"/> 5. College	<input type="checkbox"/> 6. Post-College	
11.	Occupation: (If the answer is <u>Yes</u> go to question 13 and if <u>No</u> go to the next question):				
		<input type="checkbox"/> 1. Yes	<input type="checkbox"/> 2. No		
12.	If you have <u>NO</u> occupation, is it because of you having ESRD?			<input type="checkbox"/> 1. Yes <input type="checkbox"/> 2. No <input type="checkbox"/> 3. Not sure	
13.	Are you living	<input type="checkbox"/> 1. Alone	<input type="checkbox"/> 2. With Family	<input type="checkbox"/> 3. With friend	
		<input type="checkbox"/> 4. Other		Specify Other:	
14.	Are you living in?	<input type="checkbox"/> 1. Urban city	<input type="checkbox"/> 2. Rural area	<input type="checkbox"/> 3. Mixed	

Kidney Dialysis patient's Survey			
Disease Profile:			
15. Primary diagnosis:	<input type="checkbox"/> 1.Diabetes	<input type="checkbox"/> 2.Hypertension	<input type="checkbox"/> 3.DM & HTN
	<input type="checkbox"/> 4.Genetics	<input type="checkbox"/> 5.Glomerulonephritis	<input type="checkbox"/> 6.Urological
	<input type="checkbox"/> 7.Other	Specify Other:	
16. What are the markers used to diagnose you as having ESRD?	<input type="checkbox"/> 1.Blood Test	<input type="checkbox"/> 2.Urine Test	<input type="checkbox"/> 3.eGFR
	<input type="checkbox"/> 4.Imaging Tests	<input type="checkbox"/> 5.Kidney biopsy	<input type="checkbox"/> 6.Nephrologists' Opinion
	<input type="checkbox"/> 7.Others	Specify Other:	
17. Co- Morbidity:	<input type="checkbox"/> 1.Diabetes	<input type="checkbox"/> 2.Hypertension	<input type="checkbox"/> 3.DM & HTN
	<input type="checkbox"/> 4.Genetics	<input type="checkbox"/> 5. Cardiovascular	<input type="checkbox"/> 6. Vascular disease
	<input type="checkbox"/> 7.Other	Specify Other:	
18. Date of 1 st diagnosis with ESRD:	<input style="width: 100%;" type="text" value="..... / /"/>		(Day / Month / Year)
19. When did you start dialysis?	<input type="checkbox"/> 1.Immediately after diagnosis (0-3m)	<input type="checkbox"/> 2.Long time after (More than 3 months)	
20. Date of 1 st dialysis:	<input style="width: 100%;" type="text" value="..... / /"/>		(Day / Month / Year)
21. Treatment modality:	<input type="checkbox"/> 1.HD	<input type="checkbox"/> 2.HDF	<input type="checkbox"/> 3.PD
	<input type="checkbox"/> 4.Mixed		
22. Number of dialysis sessions per week:	<input type="checkbox"/> 1.One	<input type="checkbox"/> 2.Two	<input type="checkbox"/> 3.Three
	<input type="checkbox"/> 4.Varied		
23. Total hours of dialysis per week:	<input type="checkbox"/> 1. 1-4 hours	<input type="checkbox"/> 2. 5-8 hours	<input type="checkbox"/> 3. 9-12 hours
	<input type="checkbox"/> 4.>12 hours		
24. What time of day do you START your dialysis treatments?	<input type="checkbox"/> 1.AM		<input type="checkbox"/> 2.PM
	<input type="checkbox"/> 3.Varied		
25. Is your dialysis timing fit with your life's system?	<input type="checkbox"/> 1.Yes		<input type="checkbox"/> 2.No
26. Type of vascular	<input type="checkbox"/> 1.Perminant AVF	<input type="checkbox"/> 2.Perminant AVG	<input type="checkbox"/> 3.Permanent Thrill
	<input type="checkbox"/> 4.Permanent Bruit	<input type="checkbox"/> 5.Temporary P.Cath	<input type="checkbox"/> 6.Temporary FVC
	<input type="checkbox"/> 7.Temporary JVC	<input type="checkbox"/> 8.Other	
27. Are you comfortable with the type of vascular access do you have:	<input type="checkbox"/> 1.Yes		<input type="checkbox"/> 2.No
28. Transferred from other RDC in the Previous years:(If NO go to question 30):	<input type="checkbox"/> 1.Yes		<input type="checkbox"/> 2.No
29. If yes when transferred:	<input style="width: 100%;" type="text" value="..... / /"/>		(Day / Month / Year)
30. Are you planning to do kidney transplantation?	<input type="checkbox"/> 1.Yes	<input type="checkbox"/> 2.No	<input type="checkbox"/> 2. Not sure
31. Had you ever did renal transplantation? (If NO go to question 33)	<input type="checkbox"/> 1.Yes		<input type="checkbox"/> 2.No
32. Had your renal transplantation failed?	<input type="checkbox"/> 1.Yes		<input type="checkbox"/> 2.No

Kidney Dialysis patient's Survey		
Risk factor at incidence:		
33. Proteinuria:	<input type="checkbox"/> 1.Yes	<input type="checkbox"/> 2.No
34. Hypertension:	<input type="checkbox"/> 1.Yes	<input type="checkbox"/> 2.No
35. Family history of ESRD:	<input type="checkbox"/> 1.Yes	<input type="checkbox"/> 2.No
36. High dietary protein intake:	<input type="checkbox"/> 1.Yes	<input type="checkbox"/> 2.No
37. Low socio-economic status:	<input type="checkbox"/> 1.Yes	<input type="checkbox"/> 2.No
38. Obesity:	<input type="checkbox"/> 1.Yes	<input type="checkbox"/> 2.No
39. Diabetes:	<input type="checkbox"/> 1.Yes	<input type="checkbox"/> 2.No
40. Anaemia:	<input type="checkbox"/> 1.Yes	<input type="checkbox"/> 2.No
41. Dyslipidaemia:	<input type="checkbox"/> 1.Yes	<input type="checkbox"/> 2.No
42. Nephrotoxins (NSAIDs, antibiotics, radiological contrast, light chains):	<input type="checkbox"/> 1.Yes	<input type="checkbox"/> 2.No
43. Smoking:	<input type="checkbox"/> 1.Yes	<input type="checkbox"/> 1.No <input type="checkbox"/> 2.X-smoker
44. Primary renal disease:	<input type="checkbox"/> 1.Yes	<input type="checkbox"/> 2.No
45. Cardiovascular disease:	<input type="checkbox"/> 1.Yes	<input type="checkbox"/> 2.No
46. Urological disorders (obstruction, recurrent urinary infections):	<input type="checkbox"/> 1.Yes	<input type="checkbox"/> 2.No
47. Limited access for RRT service	<input type="checkbox"/> 1.Yes	<input type="checkbox"/> 2.No
48. Environmental factors (e.g weather, pollution):	<input type="checkbox"/> 1.Yes	<input type="checkbox"/> 2.No
49. Sedentary lifestyle	<input type="checkbox"/> 1.Yes	<input type="checkbox"/> 2.No
50. Health care believes	<input type="checkbox"/> 1.Yes	<input type="checkbox"/> 2.No
51. Cultural factors such as delayed presentation and acceptance of RRT:	<input type="checkbox"/> 1.Yes	<input type="checkbox"/> 2.No
52. Late diagnoses:	<input type="checkbox"/> 1.Yes	<input type="checkbox"/> 2.No
53. Late referral:	<input type="checkbox"/> 1.Yes	<input type="checkbox"/> 2.No
Impact of ESRD and RRT on patients:		
54. My kidney disease interferes too much with my life:	<input type="checkbox"/> 1.Yes	<input type="checkbox"/> 2.No
55. I feel like a burden on my family and on the community:	<input type="checkbox"/> 1.Yes	<input type="checkbox"/> 2.No
56. I feel frustrated and occupied with worries while dealing with my kidney disease:	<input type="checkbox"/> 1.Yes	<input type="checkbox"/> 2.No
57. I do not have sufficient income because of my ESRD and RRT treatments:	<input type="checkbox"/> 1.Yes	<input type="checkbox"/> 2.No
58. What do you think is the cause of your renal failure?		
Death Profile:		
59. Date of death:	<input style="width: 200px;" type="text" value="..... / /"/>	(Day / Month / Year)
60. Cause of death:	
61. Age on death:	<input style="width: 50px;" type="text" value=""/>	Years
End of the Questionnaire		

Appendix E – Sample of published and unpublished data gathered during field work

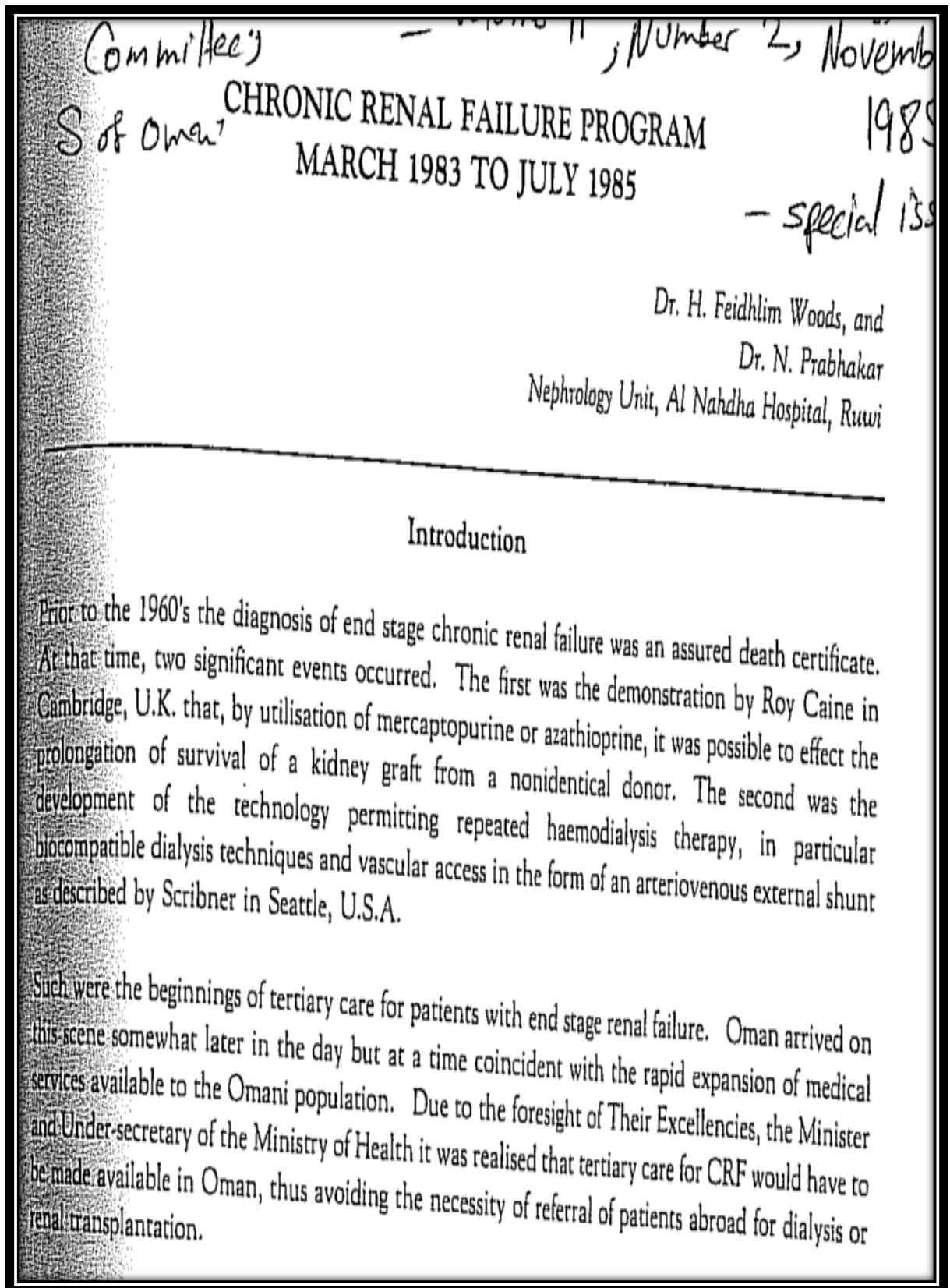
E-1 (MOH annual health report 2005 – renal dialysis)

صفحة رقم 27.7 الفصل السابع: استخدام الخدمات الصحية
Page No. 7 - 37 Chapter Seven: Utilization of Health Services

جدول 25.7: تحميل الكلى في مؤسسات وزارة الصحة خلال عام 2005
Table 7-25: Renal Dialysis in Ministry of Health Institutions during 2005

Health Institutions	Indicator	المؤشر	يناير	فبراير	مارس	أبريل	مايو	يونيو	يوليو	أغسطس	سبتمبر	أكتوبر	نوفمبر	ديسمبر	الوضع كما هو في 31/12/2005
			Jan	Feb	March	April	May	June	July	Aug	Sept.	Oct	Nov	Dec	Status as on 31/12/2005
[Redacted]	No. of beds	عدد الأسرة	6	6	6	6	6	6	6	6	6	6	6	6	6
	No. of Patients	عدد المرضى	33	36	33	21	22	26	20	22	21	20	23	22	22
	Total Number of Sessions	إجمالي عدد جلسات الغسيل	334	321	309	307	318	296	266	280	284	326	339	376	3,756
	Mean No of Sessions per patient	متوسط عدد الجلسات للمريض	10.1	8.9	9.4	14.6	14.5	11.4	13.3	12.7	13.5	16.3	14.7	17.1	12.6
[Redacted]	No. of beds	عدد الأسرة	42	42	42	42	42	42	42	42	42	42	42	42	42
	No. of Patients	عدد المرضى	208	215	223	224	210	215	214	213	213	218	218	223	223
	Total Number of Sessions	إجمالي عدد جلسات الغسيل	2,354	2,198	2,497	2,390	2,418	2,301	2,246	2,334	2,223	2,445	2,342	2,465	28,213
	Mean No of Sessions per patient	متوسط عدد الجلسات للمريض	11.3	10.2	11.2	10.7	11.5	10.7	10.5	11.0	10.4	11.2	10.7	11.1	10.9
[Redacted]	No. of beds	عدد الأسرة	-	-	-	-	5	5	5	5	5	5	5	5	5
	No. of Patients	عدد المرضى	-	-	-	-	16	16	17	17	17	17	17	17	17
	Total Number of Sessions	إجمالي عدد جلسات الغسيل	-	-	-	-	214	208	217	226	202	210	195	208	1,680
	Mean No of Sessions per patient	متوسط عدد الجلسات للمريض	-	-	-	-	13.4	13.0	12.8	13.3	11.9	12.4	11.5	12.2	12.5
[Redacted]	No. of beds	عدد الأسرة	11	11	11	11	11	11	11	11	11	11	11	11	11
	No. of Patients	عدد المرضى	56	54	57	57	62	51	52	46	50	50	52	49	49
	Total Number of Sessions	إجمالي عدد جلسات الغسيل	630	575	549	605	668	656	595	635	548	684	577	569	7,291
	Mean No of Sessions per patient	متوسط عدد الجلسات للمريض	11.3	10.6	9.6	10.6	10.8	12.9	11.4	13.8	11.0	13.7	11.1	11.6	11.5
[Redacted]	No. of beds	عدد الأسرة	9	9	9	9	9	7	7	7	7	7	14	14	14
	No. of Patients	عدد المرضى	38	36	36	38	35	36	36	36	37	37	55 ⁱⁱ	54	54
	Total Number of Sessions	إجمالي عدد جلسات الغسيل	505	423	448	444	471	438	444	471	417	442	527	670	5,700
	Mean No of Sessions per patient	متوسط عدد الجلسات للمريض	13.3	11.8	12.4	11.7	13.5	12.2	12.3	13.1	11.3	11.9	9.6	12.4	12.0

E-2 (Published article about chronic renal failure, 1985)



E-3 (Sample of aggregated data provided by the RRT register of Oman)

Treatment Type	Sex	No Of Patients
Funct Tx	F	399
Funct Tx	M	556
On APD	F	23
On APD	M	19
On CAPD	F	19
On CAPD	M	15
On HD	F	525
On HD	M	636

Pt_Regn	No Of Pats
Muscat	1296
Batinah	1036
Dakhilia	590
Sharqiah	517
Dhofar	390
Dhahira	230
Unk	67
Msandam	50
Buraimi	45
Wusta	7

Appendix F - Published articles on Oman's RRT population (1980-2013)

	Title	Authors & published in	Date of publication	Design
1.	Al-Nahda Hospital Milestones	No nominated authors - Hospital Newsletter published in OMJ	1984	R
2.	Health services in Oman: the past 15 years	Al-Mughairy - Post graduate medical education committee - Oman Newsletter	1985	R
3.	Chronic kidney failure program March 1983- July 1985	Woods and Prabhakar – Post graduate medical education committee - medical newsletter	1985	OC
4.	High mortality among recipients of bought living-un-related donor kidneys	Salahudeen and et al.- Lancet	1990	OC
5.	Prevalence of antibodies to hepatitis C virus among Omani patients with kidney disease	Al-Dhahry and et al. - Clinical Microbiology and Infection	1993	CS
6.	Omani experience with a heterogeneous group of kidney transplant recipients over a 10-year period	Aghanashinikar and et al.-Transplant Proceedings.	1993	NA
7.	Hepatitis B, delta and HIV infections among Omani patients with kidney diseases: a seroprevalence study	Al-Dhahry and et al. - Annals of Saudi Medicine.	1994	CS
8.	Echocardiographic findings in ESRD on regular haemodialysis	Marei and et al. - OMJ	1995	CS
9.	Left ventricular filling patterns in ESRD and the impact of haemodialysis	Marei and et al. - OMJ	1995	CS
10.	Defective clonidine-induced growth hormone secretion and normal thyroid and kidney functions in prepubertal children with chronic kidney insufficiency (CRF)	Soliman and et al. - Journal of tropical paediatrics	1995	CS
11.	Pregnancy in kidney transplantation recipients: outcome and complications in 44 pregnancies	Al-Hassani and et al. - Transplant Proceedings	1995	NA
12.	Kidney failure and transplantation activity in the Arab World. Arab Society of Nephrology and Kidney Transplantation	Abomelha - Nephrology Dialysis Transplantation	1996	CS
13.	Attitude to cadaveric organ donation in Oman: preliminary report	Kehinde and et al. - Transplan proceedings	1998	NA
14.	Renal replacement therapy in Sultanate of Oman	Al-Marhuby - Saudi Journal of Kidney Disease transplant	1998	R
15.	Malignant disease in patients with long-term kidney transplants	Saifudeen and et al.- OMJ	1999	CR
16.	The first glycopeptides- intermediate Staphylococcus aureus in Oman	Elhag and et al. - Clinical Microbiology and Infection	2000	CR
17.	Current issues and problems of transplantation in the Middle East: the	Shaheen and et al. - Transplantation	2001	NA

	Arabian Gulf	Proceedings		
18.	Living kidney donation for the mentally impaired. A case report	Mohsin N. and et al. - Transplantation Proceedings	2003	CR
19.	Hypomagnesemia as a cause of severe cardiac arrhythmias in the immediate postoperative: a kidney transplant case report	Mohsin N. and et al. - Transplantation Proceedings	2003	NA
20.	Rapid resolution of mycophenolate associated diarrhoea with a small dose of octreotide: a case report	Mohsin N. and et al. - Transplantation Proceedings	2003	CR
21.	Complete reversal of an acute rejection treated for four months after resuming dialysis: a case report	Mohsin N. and et al. - Transplantation Proceedings	2003	CR
22.	WHO study (EMRO SPLT GRANT – TSA 03/23) – Research proposal on “frequency of diagnosed hypertension, proteinuria, haematuria, urinary tract infection impaired kidney function and their geographical distribution amongst different age group of individuals in Sultanate of Oman.”	Principle, Al-Marhuby - Nephrology Services Oman, Ministry of Health, Muscat Booklet published by MOH on the national level	2004 – 2005	CS
23.	Low tacrolimus dose requirements in kidney transplant recipients in the Omani population: implications for pharmacogenetics?	Mohsin N. and et al. - Transplantation Proceedings	2005	OC
24.	High incidence of early post transplantation DM in Eastern population	Mohsin N. and et al. - Transplantation Proceedings	2005	OC
25.	Complete regression of visceral Kaposie’s Sarcoma after conversion to sirolimus	Moshin N. and et al. – Exp Clin Transplant	2005	CR
26.	Incidence, prevalence and treatment of ESRD in the ME	Abboud Omar - Ethnicity and Disease	2006	RW
27.	Prevalence and predictors of microalbuminuria in patients with type 2 DM: a cross-sectional observational study in Oman	Al-Futaisi and et al. - Diabetes Research and Clinical practice	2006	CS
28.	Donor Gender Balance in a living-related kidney transplantation program in Oman	Mohsin and et al. Transplantation Proceedings	2007	OC
29.	The Gulf Survey on anaemia management (GSAM 2005)	Alsuwaida and Alwakeel - Saudi Journal of Kidney Disease transplant	2007	CS
30.	Retinal injury as an early manifestation of post-transplant thrombotic microangiopathy: recovery with plasma exchanges and conversion to sirolimus: case report and review of literature	Mohsin N. and et al. - Transplantation Proceedings	2007	CR
31.	The history of Renal transplantation in the Arab World: a view from Saudi Arabia	Al-Sayyari - American Journal of Kidney Diseases	2008	RW
32.	Prophylaxis for opportunistic infections for kidney transplantation recipients at the Royal Hospital in Oman	Al-Raisi and et al. - OMJ	2009	OC
33.	Risk factors for CKD in Omani	A-Nassry -	2009	HCBS

	populations: a hospital based case-control study	Medical Library -SQU		
34.	Reasons of preclusion of living-related donor kidney transplants in Oman	Mohsin and Metry - Journal of the Middle East Society for Organ Transplantation	2010	OC
35.	Transplant kidney artery false aneurysm: case report and literature review	Al-Wahaibi and et al.- OMJ	2010	CR
36.	Attitude of the Omani population toward organ transplantation	Mohsin N and et al. - Transplant Proceedings	2010	CS
37.	Diabetic nephropathy in the Arab World	Farage and Al-Wakeel – Nephron Clinical Practice	2011	RW
38.	Epidemiology and aetiology of dialysis-treated ESRD in Libya	Alashek and et al. - BMC Nephrology	2012	CS
39.	Epidemiology of ESRD in the countries of the GCC: a systematic review	Hassanien and et al. - J R Soc Med Sh Rep	2012	SRW
40.	Prevalence and risk factors of DN in Omani Type 2 diabetics in Al-Dakhiliyah	Alrawahi and et al. - OMJ	2012	CS
41.	Nutritional assessment of Omani patients with diabetes and CKD: a case control study	Waly and et al. - FASEB Journal	2012	CS
42.	CKD in Arab World: a call for action	Farag and et al. - Nephron - Clinical Practice.	2013	RW
43.	Paediatric versus adult kidney transplantation activity in Arab countries	Saeed - Saudi Journal of Kidney Disease transplant	2013	CS
44.	Fibro-polycystic disease of the liver and kidney in Oman	Al-lawati - Arab Journal of Gastroenterology	2013	OC
R, report; RW, review; OC, observational cohort; CS, cross sectional; NA, either not available or not accessible; CR, case report; SRW, systematic review; HCBC, hospital case based case.				

Appendix G - Field notes and general observations with discussion

During data collection, some differences were noticed between the four locations of this study. RDC1 was the most organised and well-supplied dialysis centre. It was a very busy RDC but had nearly sufficient staff, an assigned dietician, an assigned pharmacist, and nearly sufficient nephrologists. However, this RDC was not prepared to deal with critical situations that members of the haemodialysis population may encounter at any moment. Most of the patients in this RDC were friendly and felt as if the RDC staff were part of their families. However, patients made some comments as follows: females requested separate halls apart from the males; patients asked to stop the night dialysis because they preferred to be at home at night, and also it is very difficult to find transportation at night; patients would prefer to have a spacious, separate dining room because at present they had to eat in the waiting areas, which was not comfortable. The staff asked for more staff to help in running the centre smoothly, and requested more training programmes to help the nephrology team deal with critical and emergency cases.

RDC2 serve the population of subdivision 1 as well as RDC1, but RDC2 was the default RDC for subdivision 1, because it is built within the referral hospital of the governorate, and it is prepared to deal with any emergency that dialysis sub-population of subdivision 1 may encounter. RDC2 was the smallest and the oldest dialysis centre of the four locations of this study. The patients and staff in this RDC asked to enlarge the RDC or even to shift it to another spacious place where they can have separate halls for males and females, and separate dining room and waiting area. RDC2 did not have a dietician or pharmacist for their patients.

RDC3 was a very busy, old and small RDC. The corridors were full of boxes and resources because the RDC lacks sufficient space in which to store things. This RDC did not have sufficient staff; the patients were crowded in the main hall, and there was no separation of females from males. There was no dietician or pharmacist, and the nephrologists have long shifts. RDC3 had a completely paper-based documentation system where it was difficult to access all the details of the patients.

RDC4 is located in a large referral hospital and should handle all critical cases, as RDC3 cannot. However, this RDC was crowded and working on 24-hour shifts to accommodate the increasing number of patients assigned for dialysis. Genders were mixed in the halls.

The patients wished to have some flexibility in their timetable, but unfortunately the timetables were fixed, and very difficult to change. The patients reported that it was very difficult to access the dialysis centre directly in cases of emergency, and instead they have to go to the main emergency department of the hospital to go through all the routines there before being moved upstairs to the RDC for care. This prolongs their pains and suffering.

Many patients reported that their kidney failure was because of their high blood pressure, which they either discovered very late or neglected to get treatment for. During dialysis sessions some patients would be sleeping, some keeping silent watch on others or looking at their mobile phones, and some were chatting with their fellow dialysis patients. There were no social workers to deal with these patients' fears and negative thoughts, and the staff were busy with other duties of care. In Oman, the care of the psychological status of the patient is part of the staff nurses' responsibilities unless there are social workers available to take over this duty.

Some patients said that they were ignorant and did not know what haemodialysis meant: they simply thought it was the process of taking the kidney out of the body, washing it and returning it. These patients had not had anyone to explain to them at that stage what kidney failure is, what options were available for them, what the best options were for them, and what the best ways to receive the treatment were.

A number of patients expressed their extreme sadness at witnessing some of their fellow dialysis patients passing away in front of their eyes, or sometimes hearing that a patient had had a road traffic accident and passed away on the way to or from dialysis sessions.

As the kidney failure population - and especially the dialysis sub-population - are highly vulnerable, have a restrictive timetable, with less freedom to travel, and have a low quality of life in general, these patients need sustainable support to allow them to live happily. The patients' requests during the data collection and field research are not impossible to achieve. First of all, all existing RDCs are not criticized here, and they were running and serving the needs of the kidney failure population reasonably well. However, satisfying the patients' needs is always an aim to ensure. Therefore, RDCs should have a convenient infrastructure for these patients, such as separate renal dialysis centres, that are spacious, equipped with all facilities to handle these cases efficiently and safely, and with an independent emergency department for this population. These centres have to be spacious considering the Omani culture where patients of different genders feel more comfortable

when separated in different dialysis halls. These RDCs should be accessible for patients, and no patient should be allowed to travel a great distance for dialysis. Otherwise home dialysis training for the peritoneal dialysis should be initiated. Transportation might be provided for these patients, since they have pre-planned, frequent and known timetables for dialysis. Sufficient and trained staff should be provided, such as nephrologists, renal nurses, dieticians, pharmacists, machinery technicians, and social workers. The renal team should ensure that they run effective educational programmes for patients pre- and during dialysis or kidney transplantation. Timetables might be more flexible, and show care for patients' circumstances where possible.

- ***Haemodialysis dose, duration and timing***

In RDC1, the number of dialysis sessions per week was varied, but commonly limited to two or three sessions. Most of the participants (92.7%) were assigned three sessions per week and spent an average of 9-12 hours on a dialysis machine each week. More than half of the participants came for their dialysis session in the afternoon or evening; RDC1 is open 24 hours a day. Most of the participants ($n = 104 = 84.6\%$) were happy with their dialysis session timings; the small number of participants who were not happy ($n = 19 = 15.4\%$) were those who were particularly attending night sessions (Figure 8-8).

Most of the RDC2 participants ($n = 37 = 84.1\%$) came for three sessions per week (at least nine hours of dialysis per week), and the remaining seven participants (15.9%) followed a pattern of two-session weeks (at least five hours of dialysis per week). Most of the RDC2 participants had differing timings for dialysis, sometimes in the morning and other times in the afternoon. This RDC only opens for two shifts, from 7am-2pm and 2pm-9pm. The majority of the participants ($n = 41 = 93.2\%$) were satisfied with their dialysis timetable (Figure 8-8).

Most of the participants ($n = 38 = 49.4\%$) in RDC3 attended three dialysis sessions per week and for a minimum of nine hours of dialysis weekly. This centre was open from 7am until 9pm, so participants attended a specific timetable whereby they should complete their dialysis before the closing time at 9pm. They might have had morning, afternoon or evening schedules, or even a combination. Most of the participants ($n = 72 = 93.5\%$) were satisfied with their timetables and had no problems with them (Figure 8-8).

Most of the RDC4 participants ($n = 70 = 72.2\%$) followed a dialysis timetable of two sessions per week, and a quarter of them ($n = 24 = 24.7\%$) were on three sessions per week. Two participants (2.1%) said they had a mixed schedule of two or three sessions per week, and one participant (1%) said s/he was coming only once a week for dialysis. RDC4 was open 24 hours, so only 23 participants (23.7%) had morning dialysis sessions, and the remainder either had evening sessions ($n = 40 = 41.2\%$) or a mixed timetable where they started the session in the morning but completed it during the afternoon. A few participants attended night sessions. Most of the participants ($n = 79 = 81.4\%$) found their dialysis timetable fit with their lifestyle and were satisfied with it (Figure 8-8).