

Poly cystic ovarian syndrome (PCOS) in Oman: Effects in pregnancy, psychosocial aspects of infertility and quality of infertility care from patients' and healthcare providers' perspectives

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BHSc MD MPH

Thesis submitted to the

University of Nottingham for the degree of

Doctor of Philosophy

April 2019

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Abstract

Background

Poly cystic ovarian syndrome (PCOS) is a common endocrine problem among women of reproductive age. The estimated prevalence is 6-12% worldwide using the Rotterdam diagnostic criteria. A recent study showed a prevalence of 7% in Oman. Evidence is lacking about the association of PCOS and the reproductive health of women in the Middle East including Oman. Despite extensive research, it is still unclear whether PCOS carries an increased risk of adverse outcomes in mothers and their newborns. PCOS is also a common cause of anovulatory infertility. However, the psychosocial impact of infertility experienced by women with PCOS is a neglected research area. Studying the lived experience of infertility among Omani women is important, given the cultural context of the region where no evidence is yet available. Furthermore in attempting to evaluate fertility services it is vital to understand both patients' and healthcare providers' (HCPs) perceptions on the care provided in fertility clinics to identify ways in which this aspect of care could be improved.

Aim

The aim of this thesis was to investigate the impact of PCOS on different reproductive outcomes among Omani women. First, it aimed to examine the effects of PCOS on pregnant women and their newborns. Second, it sought to understand the psychosocial impact of infertility among women with PCOS, within the Omani culture. Thirdly, it aimed to understand both women's and HCPs' views and

perceptions on the current available fertility services, particularly the attention given to patients' emotional wellbeing.

Methods

Three studies were carried out in two tertiary centres, located in the capital city of Oman -Muscat.

The first was a quantitative cohort study using patients' electronic hospital health records to assess the association between PCOS and pregnancy outcomes in women (gestational diabetes mellitus (GDM), pregnancy induced hypertension (PIH), preeclampsia, miscarriage, stillbirth, preterm-delivery and undergoing caesarean section (C-section)) and their newborns (macrosomia, low weight for gestational age (LWGA), low APGAR score, and admission to neonatal unit (NICU)). The unit of analysis was the pregnancy. Multilevel multivariable regression models were used to obtain adjusted odds ratios (ORs) for outcomes along with 95% confidence intervals (95% CI) using STATA software.

Two qualitative studies using semi-structured interviews were conducted. The first explored the psychosocial experience of infertility among Omani women with PCOS and their experiences with fertility care. The second study explored HCPs' views on the quality of services provided in fertility clinics including the extent to which emotional support is offered to patients. Interviews were digitally audio-recorded, transcribed verbatim and analysed using the framework approach.

Results

A study population of 1,939 pregnancies were enumerated from a total of 922 women of which 305 (contributed 529 pregnancies) had a diagnosis of PCOS. Women with PCOS were more likely to develop adverse metabolic outcomes during pregnancy compared to women without PCOS. They were more likely to develop GDM (odds ratio (OR) =2.31, 95% CI 1.38 - 4.10); and PIH (2.65, 1.11-6.31), however no difference was found in the odds to develop preeclampsia (2.86, 0.66-12.46). Adverse birth outcomes of miscarriage and preterm delivery were also higher in pregnancies where the mother had PCOS (3.41, 2.23–5.22) (3.13, 1.61-6.10), as was the risk of undergoing emergency C-section (3.64, 1.61-8.23), however no difference was found in the risk of stillbirth between the two groups (1.07,0.28-4.17). Compared to newborns to mothers without PCOS, newborns to mothers with PCOS were not at increased risk of macrosomia (0.78, 0.04-14.70), LWGA (0.877, 0.34-2.28), low APGAR score (0.53, 0.08-3.63) or admission to NICU (0.48, 0.43-5.47).

Results from the qualitative interviews with women (n=20) showed that culturally, women were expected to conceive soon after marriage and most participants felt they were blamed for any delay. Participants revealed experiencing psychological and social pressures from their in laws, with admissions that their husbands were encouraged to consider remarrying. The majority of women mentioned being emotionally supported by their partners, however marital tensions were apparent in couples that had been experiencing infertility for longer. Women also shared feelings of guilt about being unable to bear children, loneliness, jealousy and feeling

inferior to other women with children. The treatment process was also stressful for these women, where failed attempts seemed to worsen their emotional instability, given the perceived social pressure.

Finding from the interviews with HCPs showed they perceived the negative emotions prevalent among their patients, and recognised the role of social and medical stressors burdening them. However HCPs admitted their inability to approach or address patients' emotional wellbeing, which was related to time constraints during the consultation due to, language barrier, the focus being to treat the organic cause, lack of training and some patients' hesitancy to share feelings, due to social constraints. Nurses felt they had a stronger rapport with patients due to the better continuity of care provided by them compared to physicians. This suggests a potential more extended role of nurses in fertility clinics in providing patients with education and counselling compared to their current marginal role.

Patients and HCPs agreed on the need for emotional support to be provided as part of standard care in fertility clinics. Given the existing social, professional and institutional barriers, this support was suggested to be best provided by a psychologist within the clinic and to be carefully labelled to avoid the social stigma associated with mental illness. There were suggestions that women with PCOS face different challenges due to the nature of the condition, and thus the need for emotional support may be greater compared to other infertile women.

Conclusions

PCOS has a negative effect on women's reproductive health. Pregnant women with PCOS are at increased risk of different metabolic and adverse birth outcomes. Therefore close antenatal monitoring is vital for early detection and control of metabolic disorders and will help timely intervention during delivery for better maternal-foetal prognosis. In addition, infertile women with PCOS experience significant psychosocial challenges particularly in terms of feeling accepted by society, given the high value placed on fertility within the culture. This pushes them to seek fertility treatment early which makes them experience additional physical and psychological strain due to fertility treatment's extensive nature. Moreover they get further disappointed to not have their emotional needs met during consultations as they wished. Therefore gaining insight into these negative psychosocial experiences of women with infertility and its treatment and understanding the barriers among HCPs to address patient's emotional wellbeing, policy makers should consider integrating emotional support as part of standard care to women in fertility clinics to better support this neglected group of women.

Acknowledgments

This thesis was supervised by Dr. Manpreet Bains, Dr. Liza Szatkowski, Dr. Linda Fiaschi and Dr. Jack Gibson at the University of Nottingham, to whom I am sincerely thankful and grateful for their continuous constructive advice, guidance and support in undertaking this research.

I would also like to thank all the women and the healthcare providers who were very eager to help and take part in this study and whom without their contribution this research would not have been possible to be completed. My deepest thanks also goes to all whom have helped and facilitated my access to patients' data in Sultan Qaboos University Hospital and Royal Hospital in Oman to create the study database.

Finally, I am so grateful for the great invaluable support of my family including my husband; Azaan ALRumhi, my mother, my in laws and my two angels; Razaan and Yusuf. I cannot thank them enough for being so patient in bearing my studies over the last three years and my time away from them, I am eternally grateful for the love, encouragement and comfort they have provided me to achieve this goal.

My dear beloved family this is dedicated to you.

List of Abbreviations

95% CI: 95% Confidence Interval

A&E: Accident and Emergency

AES: Androgen Excess Society

ANC: Antenatal Care

APGAR score: an evaluation of the newborn baby on five criteria (**A**ppearance, **P**ulse, **G**rimace, **A**ctivity, and **R**espiration)

ARTs: Assisted Reproductive Techniques/Technologies

ASRM: American Society for Reproductive Medicine

BMI: Body Mass Index

CAH: Congenital Adrenal Hyperplasia

CHD: Coronary Heart Disease

CVD: Cardiovascular Disease

C-section: Caesarean section

DM: Diabetes Mellitus

GDM: Gestational Diabetes Mellitus

HCs: Health Centres

HCPs: HealthCare Providers

HRQOL: Health Related Quality Of Life

HTN: Hypertension

ICD: International Classification of Diseases

IUI: Intra Uterine Insemination

IUFD: Intra Uterine Foetal Death

IVF: In Vitro Fertilization

LWGA: Low Weight for Gestational Age

MOH: Ministry of Health

MRN: Medical Record Number

NICU: Neonatal Intensive Care Unit

NIH: National Institute of Health

OGTT: Oral Glucose Tolerance Test

OR: Odds Ratio

PIH: Pregnancy Induced Hypertension

PNC: Postnatal Care

PCOS: Poly Cystic Ovarian Syndrome

QOL: Quality Of Life

RH: Royal Hospital

SHBG: Sex Hormone Binding Globulin

SQUH: Sultan Qaboos University Hospital

Glossary

Alopecia: loss of hair on the head; baldness

Anovulation: is a menstrual cycle during which the ovaries do not release an oocyte. Therefore, ovulation does not take place, defined as menstrual cycles of ≥36 days or <8 cycles a year

APGAR score: is an evaluation of the newborn baby on five criteria (**A**ppearance**, P**ulse**, G**rimace**, A**ctivity**, R**espiration)**.** A scale is given from 0 to 2 on each measure at 1 and 5 minutes after birth. The higher the score the better, a score less than 7 at 5 minutes of birth is considered a low APGAR score

Caesarean section: a surgical procedure in which incisions are made through a woman's abdomen and uterus to deliver her baby

Cushing's syndrome: a metabolic disorder caused by overproduction of corticosteroid hormones by the adrenal cortex and often involving obesity and high blood pressure

Gestational age: is a common term used to describe the age of the pregnancy. It is measured in weeks, from the first day of the woman's last menstrual period (LMP) to the current date or by using an ultrasound if LMP is not known. A normal pregnancy can range from 37 to 42 weeks

Hirsutism: abnormal growth of hair on a person's face and body, especially on a woman

Hypergonadism: is a condition where there is a hyper function of the gonads, and it is caused by high levels of the male sex hormone testosterone in PCOS

Hyperprolactinemia: higher-than-normal blood levels of the hormone prolactin. This hormone is made by the pituitary gland, which is located at the base of the brain. The main function of prolactin is to stimulate breast milk production after childbirth

IUFD*: intrauterine foetal death after 24 weeks of gestation and way from birth where resuscitation is not possible

Low Weight for Gestational Age (LWGA): babies with birth weight below the 10th percentile for the gestational age according to the studied population's standards.

Macrosomia: birth weight of 4000g or more (this cut of point is used in Oman based on Omani population standards)

Miscarriage: loss of the embryo before the 24th week of gestation

Neonatal Intensive Care Unit (NICU) admission: admission of newborn to an intensive care unit due to illness or prematurity

Percentile: each of the 100 equal groups into which a population can be divided according to the distribution of values of a particular variable

Placental abruption: separation of the placenta from the wall of the uterus, especially when it occurs prematurely during pregnancy

Preterm delivery: delivery before 37 weeks of gestation

Stillbirth*: foetal death after 24 weeks of gestation but just before or at time of delivery where resuscitation is possible

***These two terms are used interchangeably in the literature but with the above mentioned meanings in practice in Oman**

1 Thesis introduction

1.1 Thesis overview

Poly Cystic Ovarian Syndrome (PCOS) is one of the most prevalent endocrinopathies affecting women of reproductive age (1). It is characterized by irregular menses, hyperandrogenism, and polycystic ovaries (2). There is a wide variation in the clinical and biochemical manifestations of PCOS among affected individuals which resulted in the development of different criteria to diagnose the condition (2). Therefore the prevalence estimates of PCOS varies considerably worldwide depending on the diagnostic criteria used. A worldwide prevalence of 6-16% has been reported using the Rotterdam diagnostic criteria (3). These criteria state that women should present with two out of the three clinical presentations in order to be diagnosed with PCOS. These presentations are 1) endoscopic or ultrasound identification of enlarged ovaries with fluid filled cysts; 2) clinical or biochemical presentation of hypergonadism; 3) oligo-or anovulation(4).

Little is known about PCOS among the Omani population. This thesis presents three studies that were conducted on PCOS and reproductive health of Omani women. A quantitative retrospective cohort study investigated the effect of PCOS on the occurrence of selected metabolic and adverse birth outcomes among affected pregnant women and their newborns. Two qualitative studies using semi-structured interviews explored the experiences of infertility among Omani women with PCOS

and further explored both infertile patients' and healthcare providers' views on the quality of services in fertility clinics.

This chapter will begin by defining PCOS, its prevalence, pathophysiology, aetiology and epidemiology in Oman, effect on reproductive health of women and their newborns and its connection to infertility among affected women. Then it will move to review the literature on these aspects and the rationale underpinning the studies conducted as part of this thesis, among the Omani women. Finally, it will introduce the aims and objectives of each study.

1.2 Poly Cystic Ovarian Syndrome (PCOS)

1.2.1 Definition and clinical features

PCOS is a complex genetic endocrine disorder of women and of uncertain aetiology(5). It affects women of reproductive age and is considered the most common endocrine problem of women in this age group (18-49)(6). Common symptoms among affected women include irregular menstrual periods or no periods at all, excessive hair growth (mainly on the face, chest, back and buttocks), weight gain, thinning of scalp hair or its loss and facial acne(7). These symptoms occur due to increased androgen hormones including testosterone in their body(8). In addition there might be a presence of tiny cysts on the ovaries in pelvic ultrasound images(9). At least 50% of women with PCOS will seek fertility treatment during their reproductive life and this is mainly due to anovulation leading to sub-fertility and infertility (3, 10). However these symptoms vary in severity from one woman to another.

1.2.2 Prevalence

Although PCOS is considered to be the most common endocrinopathy among women of reproductive age, its prevalence is not yet well established(11). The wide variation of its clinical and radiological features among affected women has led to the emergence of different diagnostic criteria hence different prevalence estimates(11). Proceedings from a conference held by the United States' National Institutes of Health (NIH) in 1990 agreed on a definition of PCOS being a disorder of ovarian androgen excess(12). It stated 4 criteria to diagnose the condition: 1)

hyperandrogenemia (androgen excess: increased level of male hormone in female body); 2) oligoovulation (absence or infrequent ovulation by ovaries, defined as menstrual cycles ≥36 days or <8 per year); 3) exclusion of known disorders, such as Cushing's syndrome, hyperprolactinemia, and congenital androgen hyperplasia(CAH); 4) polycystic ovaries on ultrasound(13). Later another conference was held by experts in Rotterdam, the Netherlands, in 2003, jointly with the European Society for Human Reproduction and Embryology and the American Society for Reproductive Medicine, which has further expanded the definition of PCOS by NIH. The Rotterdam criteria stated that by exclusion of all other causes, PCOS can be diagnosed in the presence of any two of the following three features among women: 1) hyperandrogenism; 2) oligo or anovulation; 3) ultrasound evidence of ovarian cysts(2). Furthermore, the Androgen Excess Society(AES) considers hyperandrogenemia as the main disease feature, that is androgen hormone excess either biochemically and/or clinically in addition to ovarian dysfunction in a form of ovulation abnormalities or polycystic ovaries, again with the exclusion of other disorders with similar features(14).

This lack of agreement and therefore the emergence of different criteria are mainly down to the considerable heterogeneity observed in the presenting symptoms of this disorder. The worldwide prevalence of the syndrome ranges between 5% using the NIH consensus to up to 16% with the Rotterdam consensus (3, 15, 16), as shown in figure (1.1). A recent systematic review showed a prevalence of PCOS of 16.0% (95% CI 13.8–18.6%) in the Middle East, using the Rotterdam criteria(17). It is not surprising that higher prevalence estimates are reported using the Rotterdam criteria as it accepts a wider disease phenotype to label patients with the disorder.

Moreover, this variation in the syndrome's prevalence is observed not only between different countries but within countries as well, depending on the used diagnosing criteria. Taking into account the need to carry out blood tests and ultrasound images to diagnose the condition makes it logistically difficult to detect it among a representative sample of women, thus most studies were carried out among convenience samples of women who were employees(3, 18), college students(19) or blood donors(15) and on small sample size (not exceeding 400) where their representativeness of the referenced population remains questionable. It is estimated that around 70% of women with PCOS are left undiagnosed (16).

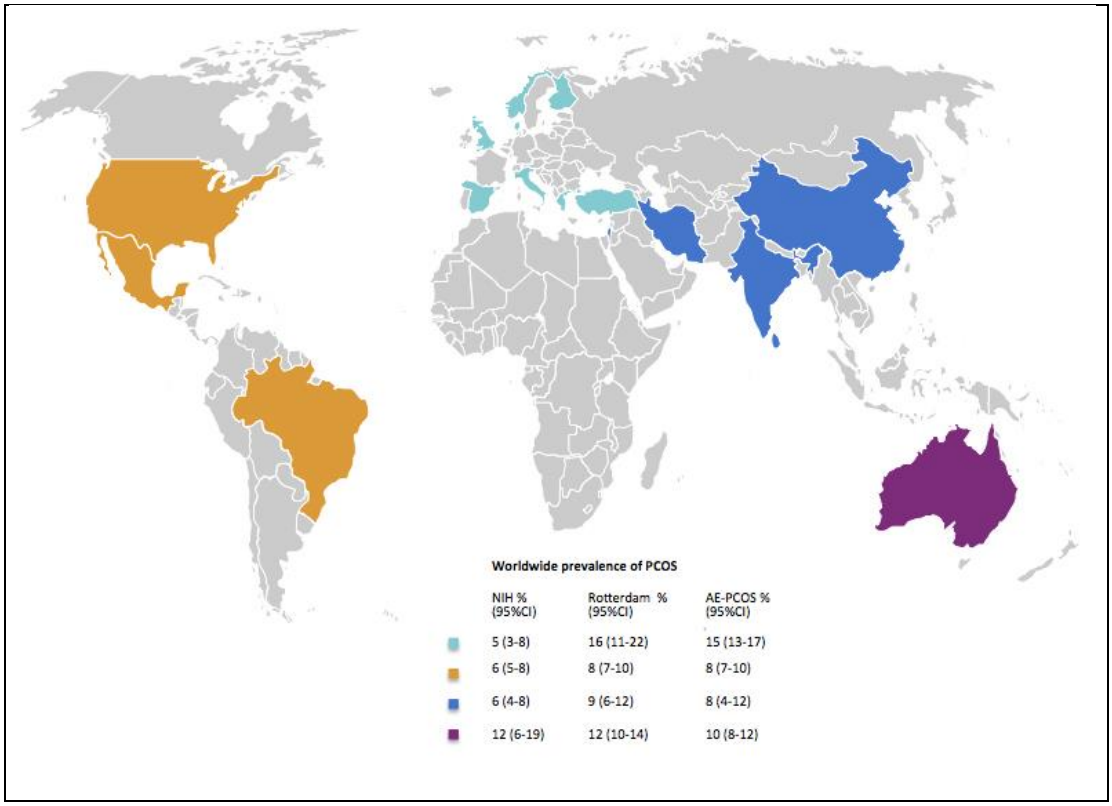


Figure 1.1: Worldwide prevalence of PCOS according to different diagnosis criteria

No data available for the countries in grey color (including Oman)

Figure source (16)

1.2.3 Aetiology and pathophysiology

The exact aetiology of the disease is not well known, however it is believed that PCOS results from multiple genetic, environmental and lifestyle factors and these mixed factors may play a role in disease severity and heterogeneity among affected women (20, 21). Hyperinsulinemia and/or hyperandrogenemia are believed to be the main hormonal imbalances underlying the aetiology of PCOS. Various genetic and environmental factors play a role in these hormonal disturbances including excess weight and ovarian and hypothalamic abnormalities (22, 23). Hyperinsulinemia was detected in 50%-80% of cases (24),similarly hyperandrogenemia was a contributor to disease pathophysiology in 60%-80% of cases(25).

Figure (1.2) illustrates the current state of understanding regarding the pathophysiology of PCOS and the interplay between various hormones of disease pathophysiology and its relation to clinical characteristics among affected women. The exact pathogenesis of the disorder is not yet fully understood and this is mainly due to the unavailability of the ideal methods to assess both insulin resistance and hyperandrogenism (26), however many studies have found an association between PCOS and insulin resistance among affected women leading to hyperinsulinemia. This compensatory high secretion of insulin due to its resistance promotes both ovarian and adrenal secretion of androgen leading to a state of androgen excess-hyperandrogenemia (2, 6, 27). Moreover, it supresses the hepatic secretion of the sex hormone binding globulin (SHBG), which worsens hyperandrogenemia by increasing the level of freely circulating androgens. Both hyperinsulinemia and hyperandrogenemia were suggested to increase the hypothalamic secretion of

gonadotrophin releasing hormone called luteinizing hormone (LH). This LH excess itself among women with PCOS is believed to further promote the secretion of androgens by the ovaries (28). Moreover it is estimated that 50% of women with PCOS are obese(29). Obesity is an independent causal factor in the disorder. Obesity increases the level of free testosterone (through increasing the level free androgen index and decreasing sex hormone-binding globulin (SHBG)) and thus worsening hyperandrogenemia (30).

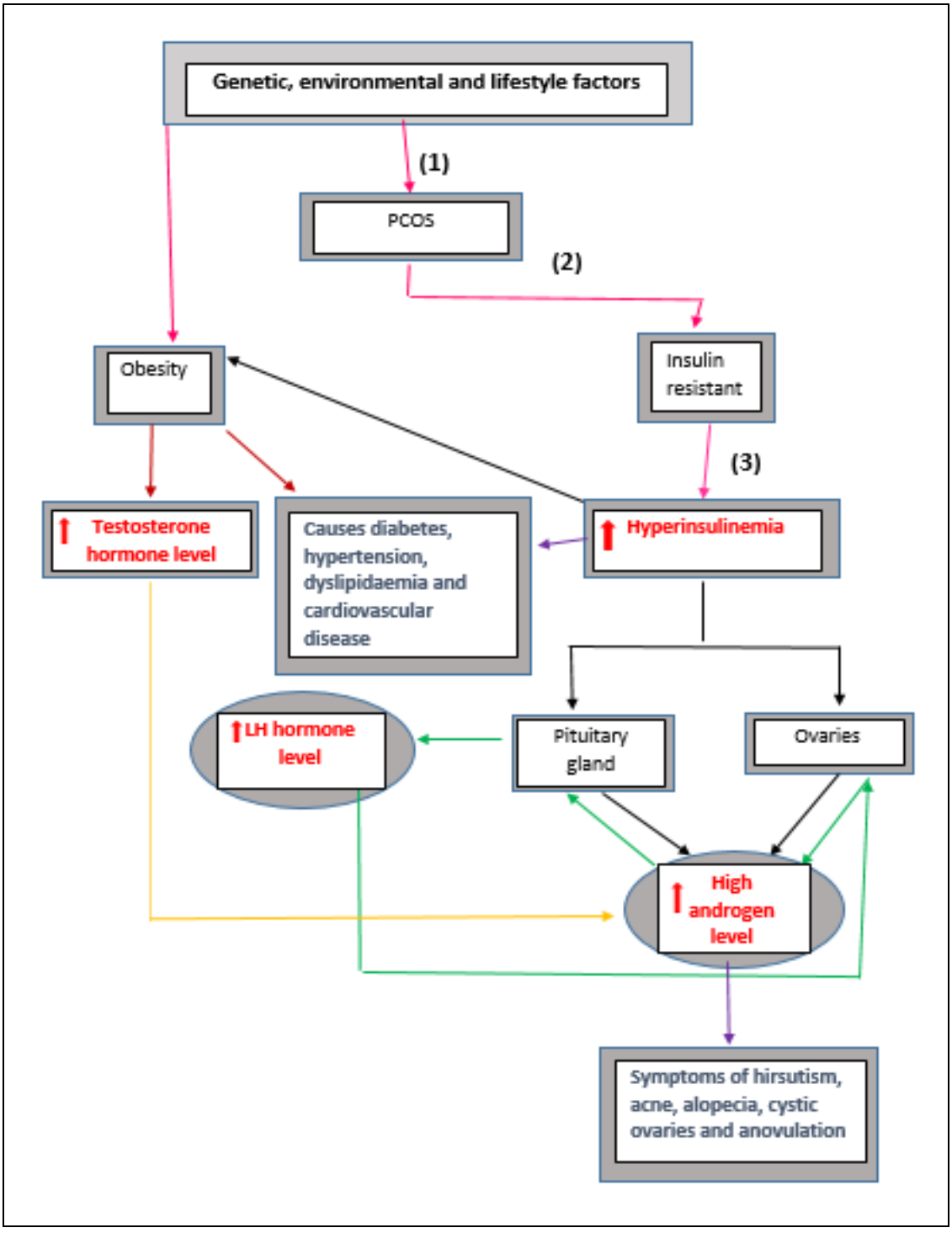


Figure 1.2: Pathophysiology and clinical symptoms of PCOS

1.2.4 Health consequences

1.2.4.1 Metabolic diseases

Studies showed an association between PCOS and many long-term metabolic health consequences among affected women. Insulin resistance among women with PCOS combined with obesity are found to be the main reasons behind their impaired glucose tolerance and the risk of having type 2 diabetes mellitus (DM) (31). Impaired glucose tolerance is defined as a high level of blood glucose above normal but not high enough for the diagnosis of diabetes mellitus and it is tested through measuring plasma glucose level 2 hours after glucose loading in a glucose tolerance test(32). Studies reported that around 20% of obese women with PCOS are at risk of developing impaired glucose tolerance before the age of 30 (33, 34). Moreover women with PCOS and impaired glucose tolerance are at a 5-10 folds higher risk to convert to frank DM when compared to controls with impaired glucose tolerance and without PCOS (35, 36). In addition, type 2 diabetes was reported to be 7 times higher among women with PCOS compared to controls (15% vs 2% respectively) (37). This is mainly down to insulin resistance among affected women(38). High body mass index(BMI) especially abdominal obesity and strong family history of diabetes are factors that play a role along with the presence of PCOS in increasing their risk to develop type 2 diabetes (35). However evidence suggests that PCOS itself is an independent risk factor to develop type 2 diabetes(39) as lean women with PCOS were also found to be at an increased risk (40, 41).

Moreover hyperandrogenemia is believed to be responsible for the increased risk of hypertension (HTN) among women with PCOS (42) compounded with

hyperinsulinemia (43, 44). A study by Chen and Yang found an increased risk for women with PCOS to develop elevated blood pressure readings with odds ratio of 3.8 (p 0.03,95% CI 1.14 to 12.74) and this was independent of age, BMI, other anthropometric, metabolic and hormonal factors(42). Another study in Brazil detected a 2-fold increase in prevalence of HTN among women with PCOS compared to controls (18.6 vs 9.9, $P < 0.05$) (45). In addition a study of the Tunisian National Institute of Nutrition involving 79 patients with PCOS, reported family history of hypertension is not a predictor of HTN among women with PCOS nor was age, suggesting PCOS being an independent risk factor for HTN among these women (46). On the other hand the inter-play of the variable factors of insulin resistance, excess androgen and obesity affect the lipid metabolism in women with PCOS. The prevalence of dyslipidaemia in women with PCOS is estimated to be around 70%(47). A meta-analysis by Wild et al. including cross sectional studies (mainly on European and American population) found increased levels of triglycerides and non-HDL cholesterol among women with PCOS (26.4 mg/l and 18.8 mg/l respectively) and lower levels of the “good” HDL-cholesterol (6mg/l) compared to their non-PCOS counterparts and these findings were regardless of their BMI status (48, 49).

Unsurprisingly, components of metabolic syndrome (also known as syndrome X) are evident among women with PCOS. This syndrome includes a cluster of metabolic conditions and these are: high blood pressure, abnormal lipid profile, increased fat around waist and high blood sugar(50). Despite metabolic syndrome being a known risk factor for cardiovascular disease (CVD) (51-54), evidence is limited when it comes to the real observed CVD morbidity and mortality among women with PCOS.

In a long-term follow up study, history of coronary heart disease (CHD) was not significant among women with PCOS compared to controls (OR 1.5, 95%CI 0.7-2.9)(55). Another study could not establish an association between PCOS and CVD among PCOS cases despite reporting their increased metabolic risk to develop it (56). Summary of metabolic outcomes from the above mentioned studies can be found in table (1.1).

Table 1.1: Summary of long-term metabolic outcomes among women with PCOS

Metabolic abnormality	Diabetes mellitus* (31)	Hypertension* (45)	Dyslipidaemia*(48)	Cardiovascular disease**(55)
Women with PCOS	15%	18.6%	Triglyceride 26.4mg/l higher Non-HDL cholesterol 18.8mg/l higher HDL-cholesterol 6mg/l lower	OR=1.5
Women without PCOS	2%	9.9%	baseline	

***significant difference (p<0.05)**
****non-significant (p=0.4)**

1.2.4.2 Malignancies

A number of studies have reported an increased risk of developing endometrial and ovarian cancer among affected women. The prolonged anovulation and therefore prolonged secretion of unopposed oestrogen leads to endometrial hyperplasia, the latter is a known adenocarcinoma precursor(57). Other common factors among women with PCOS such as null parity, obesity, exposure to infertility treatment,

hypertension and diabetes equally contribute in the development of endometrial and ovarian cancer(55, 58) . A meta-analysis by Harris et al. found an association between PCOS and both endometrial and ovarian cancer, although the association between PCOS and ovarian cancer was less clear(59). In addition, no association was observed between PCOS and risk of breast cancer(59). It is believed that these associations are complex and better designed large studies that account for all possible confounders are needed to clarify the risk of PCOS in the occurrence of these cancers.

1.2.4.3 Infertility

Infertility is defined as the failure to achieve a clinical pregnancy after 12 or more months of regular unprotected sexual intercourse(134). Anovulation is one of the main symptoms among women with the syndrome and it is the main reason for these women suffering from subfertility and infertility(60). It is estimated that at least 50% of women with PCOS will seek fertility treatment during their reproductive life(10). A cross sectional analysis from the Australian longitudinal cohort study on women's health (ALSWH), noted infertility to be experienced by 72% among a total of 309 women with PCOS compared to 16% among a total of 4547 women without PCOS ($p<0.001$)(61). Moreover PCOS accounts for 90% of anovulation cases among women attending fertility clinics(62). Some women with PCOS will ovulate occasionally and therefore succeed in carrying a pregnancy without the need for medical assistance. The American Society for Reproductive Medicine (ASRM) recommends evaluating subfertility among couples with PCOS at 6 months of failure to conceive, if couples practice regular intercourse (2-

3times/week) without using any contraceptive method(63). Lifestyle modification including weight reduction through physical activity and healthy diet is considered to be the first line of non-pharmacological treatment for obese women with PCOS(62). Evidence suggests a 5%-10% reduction of body weight over a six months period will contribute in reducing central obesity and hyperandrogenism and therefore improve ovulation rate(64). Clomiphene citrate is considered to be the first line pharmacological treatment for these women to help induce ovulation (64, 65). Around 15% of women with PCOS do not respond to a full dose of this drug (66). Current data support the use of metformin as a first line treatment in clomiphene resistant women with PCOS(67). Gonadotrophins (recombinant follicle-stimulating hormone (FSHr) or human menopausal gonadotropin (HMG)) with timed intercourse or intrauterine insemination(IUI) are considered as a second line treatment option for these patients which are high in cost, therefore tube patency test should be performed prior to commencing them(64).

The ovulation rates with the use of gonadotrophins reach up to 70%, however it has a clinical pregnancy rate of only 20% per cycle if used with timed intercourse but higher if it is used with IUI(68). Ovarian drilling is also considered as a second line therapeutic modality, however due to its invasive nature it should be preserved for clomiphene citrate resistant women and for those who need laparoscopy for another gynecological reason (as it involves general anesthesia)(66). Ovarian drilling can be performed using either electrocautery or laser and the goal is to attempt between 4 and 10 punctures and not more as it might increase the risk of premature ovarian failure(69, 70). Observational studies showed an ovulation rate between 54%-76% in the 6 months after the procedure and 33%-88% in the 12

months period and subsequently spontaneous conception ranged between 28% and 56% and 54% and 76% respectively(67). Finally in vitro fertilization (IVF) represents the third and most expensive treatment option in women with PCOS and infertility unless there is a bilateral tubal occlusion and/or reduced sperm quality where it should be considered as a first line option(64). Although women with PCOS might have a better oocyte and therefore embryo quality using IVF, the observed rates of successful pregnancies and live births did not differ compared to women without PCOS and undergoing IVF for infertility treatment (71).

1.2.4.4 Dermatological issues

The excess androgen among affected women leads to symptoms of acne, loss of scalp hair and excess hair growth on face and body (72). It is estimated that 70%-80% of women with PCOS suffer from hirsutism compared to 4%-11% of women in the general population(73). These dermatological issues are disturbing to women with PCOS as it challenges their femininity, leading to frequent dermatological consultations and treatments(74).

1.2.5 Economic burden

PCOS affects approximately 1 in 15 women in the United Kingdom and other places worldwide (15, 75-77), this is approximately around 105 million cases of PCOS across the world (78). Its widespread prevalence among women of reproductive age along with the various health related consequences represents a huge economic burden on health service. It has been estimated that the cost of

diagnosing and treating the above mentioned metabolic, reproductive and dermatologic symptoms of PCOS in the US alone exceeds $ 4 billion (10). Of this total cost 2.1% is spent on initial evaluation and diagnosis, 12.2% in providing fertility care and treatment , 14.2% in treating hirsutism, 31% in treating menstrual dysfunction and 40.5% for PCOS-related diabetes mellitus (79). This amount of health expenditure is believed to be underestimated as it accounts for patients' care only during their reproductive life span(10).

The relatively low cost allocated for evaluating and diagnosing the condition highlights the need for a better utilization of resources in early detection and intervention of the condition to possibly prevent the higher cost of its long term health consequences. No further studies were found in the literature about the economic health costs associated with the disorder, which emphasises the need for more research in this field to hopefully guide health economists on the most cost-effective methods to manage this group of women.

1.3 PCOS and the reproductive health of women

1.3.1 Metabolic outcomes in pregnancy

Population studies showed up to 73% of women with PCOS suffer from oligo-or anovulation(6). In a community-based cross sectional study in Australia (2015), 28% of women with PCOS were fertile while the other 72% suffered from subfertility (61). However some women succeed in carrying a pregnancy with or without medical assistance. Despite the extensive research, it is still controversial whether PCOS has an effect on the occurrence of adverse pregnancy and birth outcomes in

affected mothers and their newborns(72, 80-83). These include metabolic outcomes in women, namely gestational diabetes mellitus (GDM), pregnancy induced hypertension (PIH) and preeclampsia and adverse birth outcomes including preterm birth, miscarriage, stillbirth and undergoing C-section(60, 84-86).

It has been shown that placental hormones block the action of the mother's insulin hormone leading to insulin resistance, with a consequent increase in glucose concentration in the bloodstream(87). Thus the increased risk of GDM among pregnant women(88). Studies in the literature have shown many risk factors associated with GDM including obesity(89-91), age above 35 years old(92),having a family history of GDM(93) , belonging to a non-white ethnic group and being from a low socioeconomic class(94). However it is difficult to compare GDM incidence across populations due to the variation in definitions and screening programs(34).

PIH occurs in 6-17% of healthy nulliparous women and is less common among multiparous women (2-4%)(95). Approximately 1 in 4 women with PIH go on to develop preeclampsia (96). Evidence suggests a possible role of hyperinsulinemia in the development of PIH(97). Other risk factors include null parity, obesity, family history of PIH in first degree relatives, carrying multiple fetuses and age younger than 20 or older than 40 years(98). Because hyperinsulinemia is common among women with PCOS in general leading to metabolic disorders of DM and HTN, it is worth examining whether these women are also at higher risk of pregnancy related outcomes of GDM,PIH and preeclampsia compared to women without the disease.

1.3.1.1 Studies in the developed world

Since the prevalence of obesity and insulin resistance are high among women with PCOS in general(99, 100), a higher prevalence of metabolic syndromes such as GDM and PIH would be expected in women with PCOS compared to women without PCOS(34). When this has been examined, an increasing body of evidence suggests an association between PCOS and the development of both GDM, PIH and preeclampsia among affected pregnant women(34, 88, 101-103) . However this evidence is still inconclusive with mixed results.

Studies conducted to date have mostly been retrospective and have included small numbers of cases (<100)(98, 100) with improper control of significant confounders such as BMI(104, 105) and family histories of DM and HTN(29, 34, 88, 101-103, 106). Although a meta-analysis including 15 studies by Boomsma et al. involving a total of 720 women with PCOS showed a positive association between PCOS and both GDM, PIH and preeclampsia, significant heterogeneity remained even after a subgroup analysis of studies with higher validity(107). Similar heterogeneity was detected in another meta-analysis by Kjerulff et al. of studies on maternal and neonatal complications among women with PCOS(108) . In another recent meta-analysis by Qin et al. also supports the evidence of increased risk of GDM, PIH and preeclampsia among women with PCOS compared to controls(82). However, many of the included studies in the latter meta-analysis did not adjust for BMI and other confounders and were mostly conducted in Western countries(82). Table (1.2) summarises the obtained results from the meta-analyses on the various metabolic outcomes. In addition a meta-analysis of 15 studies also reported an association

between PCOS and GDM, but the significant heterogeneity among the included made this observed association questionable(109).

In contrast, among the studies that have examined the risk of GDM and cautiously controlled for BMI either concluded BMI being a better predictor of GDM than PCOS or no significant association remained between PCOS and GDM after adjusting for BMI (110) (111).

Table 1.2: Odds ratios of the metabolic outcomes among pregnant women with PCOS from three meta-analyses studies

Metabolic outcomes	**Boomsma et al.(107) OR(95% CI)***	**Kjerulff et al.(108) OR(95% CI)***	**Qin et al.(82) OR(95% CI)***
GDM	2.94 (1.70–5.08)	2.82 (1.94–4.11)	2.81 (1.99–3.98)
PIH	3.67 (1.98–6.81)	4.07 (2.75–6.02)	3.07 (1.82–5.18)
Preeclampsia	3.47 (1.95–6.17)	4.23 (2.77–6.46)	3.28 (2.06–5.22)

***Odds ratio (95% confidence interval)**

1.3.1.2 Studies in the developing world

Few studies have addressed the same question in the Eastern countries including the Middle East(100, 101, 104, 112). In a case control study in Turkey (2003) involving 38 women with PCOS who were compared to 136 patients without PCOS, no difference in GDM was detected among the two groups(100). In contrast, a case control study (2008) which included 94 Iranian participants with GDM, a significant

history of PCOS was found among cases compared to controls(101). Both studies controlled for BMI, but the small number of cases in both studies might have obscured the effect of PCOS on GDM if it had existed. A nationwide study using the Taiwan (2015) national health insurance research database involved 7,629 women with PCOS, which found PCOS to be associated with GDM when compared to a control group (OR 2.15; 95% CI 1.96 –2.37)(104). However this study failed to control for BMI as it is not routinely recorded. This does not help to conclude whether this positive observed association was due to PCOS or high BMI as it was not accounted for in the analysis.

Another body of literature supports an association between PCOS and GDM but not PIH(102, 111) or preeclampsia(103). A case control study in India (2009) including 56 age and weight matched participants showed no significant difference in the incidence of both GDM and PIH among cases compared to controls(98). Some evidence suggests an association between PIH and preeclampsia with low parity (110, 113). Therefore low or null parity might be a stronger predictor for PIH and preeclampsia than PCOS. Other studies in the region have tried to examine the association between women with PCOS and GDM on the occurrence of PIH and preeclampsia(114, 115), which does not help explain the independent role of PCOS on these outcomes. Others opted to study these outcomes among a selective population of women with PCOS undergoing assisted reproductive techniques such as ovarian drilling(116) and IVF(117) and found positive results, but the obtained results are considered ungeneralizable due to the unrepresentative nature of the selected sample to the majority of PCOS population.

A more recent meta-analysis by Yu et al. (2016) which included 40 studies (8 studies from developing countries) concluded an association between PCOS and GDM, PIH and preeclampsia; however a subgroup analysis suggested this association might be influenced by BMI and study design(118).

1.3.2 PCOS and adverse birth outcomes

Existing literature supports an association between PCOS and adverse birth outcomes in general(119-127) . However, this is not a consistent finding. Many studies have examined the incidence of miscarriage among pregnant women with PCOS compared to those without the condition. However, many of these were carried out mainly to assess miscarriage among women with PCOS following different ARTs and found a positive association(119-126). This however did not assess whether the causative factor is PCOS itself or the ARTs, particularly given that a study by Raj et al. showed PCOS not to be predictive of early pregnancy loss among women with PCOS who conceived spontaneously compared to women without PCOS(127).

Furthermore, obesity is a closely related characteristic of PCOS(75). Approximately 50% of women with PCOS are overweight or obese(128). Obesity is also linked to poor pregnancy outcomes including risk of miscarriage(129-131). A cohort study by Wang et al. (2001) found no association between PCOS and miscarriage after adjusting for participants' BMI(132). A systematic review reported the same non-significant association(133). However, the studies included in the latter, suffered discrepancies in the criteria used to identify PCOS cases, which make results

inconclusive. Another meta-analysis (2006) showed no difference in miscarriage rate among cases with PCOS and controls when both groups had undergone IVF to conceive(134). In contrast, a large Australian study (2002) has shown an increased risk of miscarriage among women with PCOS compared to control (20% vs 15%, respectively, P 0.003); however after further analysis, this was found to be mainly due to high BMI among cases rather than PCOS itself(61).

Preterm delivery is an additional adverse birth outcome that has been examined in the literature among pregnant women with PCOS. Although systematic reviews have shown a positive association between PCOS and preterm delivery, these were conducted on small series, mostly case control studies and did not control for confounders such as BMI and use of ARTs(82, 108, 135). An additional meta-analysis by Boomsma et al. (2006) also found a positive association but demonstrated a large amount of heterogeneity between the included studies(107). Contrary to these findings a cohort study (2012) with 52 Mexican women with PCOS matched by age, BMI and number of pregnancies showed a negative association between PCOS and preterm delivery(102). This negative finding was consistent with a randomized, controlled multicentre study by Vanky et al. (2010) (136) and in a study by Mikola et al. (2001) in Finland, where preterm delivery among women with PCOS was due to multiple gestations rather than PCOS(111).

On the other hand, another body of literature found a positive association. A large community based study in California (2012) including 908 diverse pregnant women with PCOS and singleton pregnancies , found preterm delivery to be more frequent among women with PCOS compared to controls(12.9% vs 7.9%,$p<0.001$) and results

from the multivariate logistic regression showed that BMI and use of fertility treatment were not predictors of the outcome(137). Another study using Swedish registry (2011) included 3787 singleton births to women with PCOS, also found PCOS to increase the odds of preterm birth compared to controls (OR 2.21,95% CI 1.69 to 2.90) and this was also independent from BMI or use of ARTs(138).

Similarly, mixed results were obtained when the prevalence of C-section was examined among women with PCOS. While two systematic reviews found women with PCOS at higher risk of undergoing C- section(82, 133) others found a negative association after a sub analysis of studies with higher validity(107, 108). A cohort study on twin pregnancies of 226 Swedish (2015) women with PCOS found no difference in the risk of C-section when compared to women with twin pregnancies and without PCOS(103). However the high risk of the control group in this study to undergo C-section due to multiple gestations might have masked the effect of PCOS on this outcome. Contrary to this, a cohort study by Roos et al. (2011) on 3787 infants born to women with PCOS showed an increased risk to be delivered by C-section (both elective and emergency) compared to controls (OR 1.18 95% CI 1.07 to 1.29) (138); this finding was independent of BMI which was adjusted for as it is a known predictor for C-section(139). Similarly a study on a small number of women (n=99) in Finland (2001) with PCOS with a singleton pregnancy found them with higher risk to deliver by C-section compared to controls(111).

Stillbirth is considered a rare pregnancy outcome(81) and it affects around 1% of all pregnancies(140). Therefore it has been much less studied in the literature among women with PCOS, given the small number of cases of PCOS and the rarity of the

outcome in most of the studies. In a case control study with 52 Mexican women (2012), there was not a significant difference in the occurrence of stillbirth among women with PCOS compared to those without the condition(102). The small number of cases in this study might have provided low power to detect this outcome. However, in a larger cohort study including 3787 births to Swedish women (2011) with PCOS, the researcher also did not find an association between PCOS and the risk of stillbirth(OR 0.90,95% CI 0.50 to 1.63) (81).

1.3.3 PCOS and adverse neonatal outcomes

Further neonatal risks for babies born to mothers with PCOS have been examined and include macrosomia, low weight for gestational age (LWGA), low APGAR score, and need for admission to a neonatal intensive care unit (NICU). Macrosomia was negatively associated with PCOS in several case control studies(100, 141, 142). However, in a larger cohort study by Roos et al. a significant incidence of macrosomia was found among infants born to mothers with PCOS compared to their controls(81). Moreover this study also found infants born to mothers with PCOS to be at higher risk of low APGAR score at five minutes(138).

LWGA has also been studied and no link to PCOS was found in many studies (83, 102, 138, 143) . However, when LWGA was systematically examined in an age and weight matched case control study of 47 infants born to mothers with PCOS compared to 180 controls, the prevalence of LWGA was significantly higher in the PCOS group compared to the control group(144) .

In a meta-analysis by Boomsma et al., infants born to mothers with PCOS were 2.3 times more likely to be admitted to a NICU than newborns of controls(86).

In summary, the available evidence on the association between PCOS and various reproductive outcomes in mothers and their newborns is conflicting. Limitations are mainly in the criteria used to diagnose the condition and in the study designs including the small sample size in most of the studies and their failure to control for important confounders. In addition, very scant research is done on Asian populations to answer this same question despite their comparable prevalence of the syndrome to that detected in western countries.

1.4 PCOS and the psychosocial aspects of infertility

Anovulation is the main reason of infertility among women with PCOS. A retrospective cohort study in the UK involved 786 women with PCOS reported 66% of them suffered infertility including 17.5% with primary infertility(145). A recent systematic review(2018) estimated a demographic prevalence of infertility (regardless of the cause) of 22.6% in the Middle Eastern and North African countries(146). To date no data are available from the Middle East on the prevalence of infertility among women with PCOS.

Infertility regardless of its cause exerts a huge emotional distress to the affected couple and especially among women, whether they are the reason behind infertility or not(147). A study demonstrated infertile women had 4 times more depressive

symptoms compared to women without fertility problems(147), and the same study found them to score higher on anxiety and less on self-assessed attractiveness and memory/concentration aspects than the control group(148, 149). Moreover evidence supports a more severe impairment on quality of life (QOL) and health related quality of life (HRQOL) among infertile women compared to infertile men(150-152).

The psychosocial experience of infertility is highly related to the sociocultural context where it is being investigated(153). Literature from the developed world has tried to prove the theory of psychosocial distress being a cause rather than a consequence of infertility(154-157). The studies that have interviewed infertile women of Western populations found dominant themes of: infertility being the central focus for women's identity(158-161), feelings of loss of control(162-164), feelings of defectiveness(160), reduced competence(163, 165, 166), statelessness and ambiguity(160, 161, 165), feelings of "alienation" from the fertile world(160, 167-170), a sense of social stigma and stress on marital and sexual relations(160, 167, 171-174).

Contrary to studies from Western societies, the evidence on the psychosocial impact of infertility from the developing world (mainly African rather than Asian or Mediterranean countries) using qualitative studies(175-185) identified themes of identity loss, divorce, physical/verbal abuse, psychological suffering, social stigma and isolation(186-196).

Having children in the developing world is associated with a woman's status not only within the couple but also within the extended family and the community at

large(197). In these societies children are considered of high social and economic value(198) and childlessness leads to social stigma, isolation and abandonment especially among women as they are often blamed for a couple's inability to conceive regardless of the biological cause(199).

In a qualitative study using focus groups to understand the social meaning of infertility among Nigerian women, there was an agreement that infertility should not be discussed in public to avoid embarrassing those who are infertile(200). It also revealed the belief that men cannot be infertile. This social pressure was mainly from in laws: in Rwanda where women who participated in focus groups reported being verbally abused by their in laws for their childlessness and some have revealed being pressurized by their husband's parents to have extramarital affairs with the hope to conceive a child(187). Infertile women are also commonly avoided in these Southeast African societies as they are believed to be witches and had given birth to children in another world and cannot do the same on earth. Moreover, many women ask their children to avoid contact with infertile women, because they think these women might harm their children out of their bitterness, or unable to take care of them, due to lack of experience(200).

Economic deprivation has been reported in some countries due to being infertile. In Gambia, under some customary laws, childless women have no right to inherit property from their husbands(201).

Infertile women in the developing world suffer higher levels of stigma compared to infertile women in the developed world(202). In these cultures motherhood is tightly connected with marriage and a woman has to prove her fertility soon after

that(202). In these societies the presumption is that women are childless only if they are infertile(153).

1.4.1 The impact of infertility among women with PCOS

A few studies have tried to capture the experience of infertility among women with PCOS. These studies used standardized measures to estimate the implications of infertility among this group of women on their psychological status and results were conflicting(166, 203-206). While some related the psychological burden among women with PCOS to their infertility status(203-205), other studies found a more determinant role of PCOS symptoms and body image issues rather than being infertile on these women's reduced psychological wellbeing(166, 207). (These studies are discussed in more details in Chapter 5, section: The experience of infertility among women due to PCOS, p 131).

No studies have solely focused on infertility and its psychosocial aspects among women with PCOS using qualitative methods. It might be assumed that the experience of infertility among women with PCOS in a defined population would be similar to other women's experiences regardless of the cause of infertility. However since studies on women's experience with PCOS symptoms found reports of them feeling less feminine than other women due to the prevalent male like symptoms including hirsutism, acne, alopecia and obesity(99, 208, 209), infertility might have a different impact on them and therefore conduction of this study is deemed

necessary to fill the gap in existing literature. Moreover, since the experience of infertility (regardless of its cause) is related to the sociocultural background of where it is being investigated, it is important to explore this in the Omani society (here also among infertile women due to PCOS) where it has not been done yet.

1.4.2 Psychosocial aspects of infertility in the Arabic and Islamic world

Islam is a religion that places an emphasis on fertility and this is associated with the tolerance of polygamy in this religion(210). Moreover Islam links marriage to procreation and to both mental and physical stability through family formation (210). Infertility in the Middle East is estimated to vary between 10-15% among married couples(211). Adoption is not the norm in Arabic and Islamic cultures and is faced with much resistance in these societies(212). Therefore, infertility is considered an issue of high concern among these women who are also always blamed for infertility(212) and are under excessive pressure to reproduce(204).

Very scant research has been done to understand the psychosocial consequences of involuntary childlessness (due to various causes) among women in the Arabic and Islamic world using qualitative methods given the cultural and religious context of this region. In a study involving 10 Iranian women, semi structured interviews revealed themes of “abuse”, “marital instability”, “social isolation”, and “loss of self- esteem”(213). In another study in Iran Nasiri et al. explored women’s experiences with PCOS symptoms and found reports of feeling inferior, ashamed and of impaired femininity compared to other women, mainly due to their infertility and menstrual disorders(99).

In a study involving 24 Turkish women which used in depth interviews to explore the encountered psychosocial problems of their infertility, common themes of stigma and social pressure were reported(214).

1.5 Patients' experiences with fertility healthcare services

Fertility treatment itself including both repeated diagnostic and therapeutic procedures is believed to compound the psychological burden on couples seeking solutions to their childlessness(167). A study found psychological and physical burden of fertility treatment to be among the top reasons for women to discontinue fertility treatment(215). Many service evaluation studies have found couples being generally satisfied with the medical part of the treatment but with mixed results when it comes to their satisfaction with the way emotional aspects of infertility and its treatment were addressed i.e. the need to a more patient centered versus a treatment centered approach in fertility clinics(216-218). In a survey involving 4 European countries, 85% of women either had not been given emotional support at all or were not satisfied with the level they had received (218). Evidence suggests that women with high levels of anxiety tend to suffer from high agitation towards treatment and have a more pessimistic view about the possibility of carrying a pregnancy successfully(219). This may in part explain the high dropout rates observed in these clinics(74), especially if patients' emotional needs are not appropriately met(220).

In a study by Schmidt et al. (1998) of Danish infertile women's experiences with treatment. women reported psychological strain and expressed that their emotional needs were not met during consultations(221). A qualitative study using semi - structured interviews with infertile couples in South Africa concluded the importance of integrating psychological counselling in infertility management to increase adherence to the treatment regime(202). In another study with 178 infertile couples in Southeastern Michigan (US)(1993), in person and telephone contacts were used to determine the factors related to patient's satisfaction with infertility treatment. This study found the most frequently mentioned reasons for satisfaction were the technical skills and the emotional support received from infertility specialists(222). Couples have also reported a major concern about healthcare providers (HCPs) in fertility care being distant emotionally and not understanding what patients go through(219, 223).

Moreover existing literature supports the effectiveness of psychosocial interventions to address mental wellbeing among infertile couples, adherent to treatment and its subsequent role on better treatment outcomes(224-226).

Nothing was found about patient's experience with infertility care in the Arabic and Islamic world, due to the limited research in this area.

1.6 Healthcare providers' perceptions of the care in fertility clinics

Nowadays patient centred approaches are being argued as an important part of healthcare, and an area for improving the quality of care(227). The quality of infertility care has focused on the safety of the medical treatment and its effectiveness in terms of outcomes such as the rate of live births(228). However it is

crucial to integrate patient centeredness to achieve high level of fertility care, given the accompanying physical and emotional stress among infertile patients(229).

Patient centeredness is described as "*providing care that is respectful of and responsive to individual patient's references, needs and values and ensuring that patient's values guide all clinical decisions*"(230). There are many dimensions of patient centeredness, part of it is coordination and integration of care, but it also includes the provision of emotional support(231). Evidence confirms that infertile patients do seek patient centred care besides effective medical treatment(231-233). Patients do pay attention to the other functional issues of treatment provided by HCPs such as the knowledge on rates of treatment's failure and success, side effects, cost, time commitment and scheduling for treatment(229). All of which add to the emotional stress of their condition. This stress can be tackled by following a patient centred approach rather than a rigid medical and professional centred pathway(234). Moreover patient centred care is associated with increased satisfaction among patients(235), increased adherence to treatment(236), decreased dropouts rates (237) and increasing both patient's quality of life(238) and HCPs job satisfaction(239, 240).

As the feedback from patients about their experiences with the healthcare received in fertility clinics is vital in helping HCPs understand patient's preferences, wishes and needs, it is also important to understand HCPs' perceptions of the care they provide. This is especially important as reports that have examined HCPs' perceptions of the care they provide, found them to be different from that of their patients(234, 241). A study by Aarts et al. whose objective was to determine to

what extent HCPs working in fertility care can estimate the level of patient centeredness practised in their clinic using an infertility patient centeredness questionnaire, found that HCPs' perception of their patients' experiences with infertility care is not in line with the patients' actual situation(234). Another study in the Netherlands tried to understand HCPs' views on patient centeredness care using in depth interviews and found that they evaluated their preferences regarding patient centeredness in fertility clinics inadequately when it was compared to their patients' feedback (241). This discrepancy between patients' and HCPs' perceptions of the quality of care was a consistent finding in other studies that have assessed the same in different fields of medical care(242-244).

More attention has been given by researchers to understand infertile patients' experiences and satisfaction with the quality of care received in fertility clinics compared to HCPs' perceptions and views of the care they provide to their patients including emotional support(198, 221, 245-248). Furthermore due to the extensive nature of fertility treatment and the amount of contact with HCPs it is important to examine HCPs' views on extent of the emotional and psychological support they provide to their patients, where research has been very minimal, worldwide.

This chapter ends by presenting the demography of Oman, the prevalence of PCOS in the region, the rationale for conducting the study and the main aims and objectives of the research presented in this thesis.

1.7 The demography of Oman

The Sultanate of Oman is located in the southeast of the Arabian Peninsula(249) figure (1.3)**.** It occupies a land area of approximately 310,000 square kilometres and host a mid-year population estimate of around 4.8 million in 2017(250). Around 55% of the population in Oman are Omani citizens while 45% are male immigrants mainly from India, Bangladesh, Pakistan, Philippines and Sri Lanka. This substantially big proportion of foreigners is due to the fast growing oil driven infrastructure that requires workforce labour (250). Oman is administratively divided into four governorates (Muscat, Dhofar, Musandam and Buraimi) and five regions (Al Batinah, Adh Dhahirah, Ad Dakhliyah, Ash Sharqiyah and AlWusta)(251). These Governorates and regions are further subdivided into 61 provinces (called Wilayats)(251).

Muscat is the capital city of Oman. It occupies a land area of 3,500 square kilometres(250).The majority of the Sultanate's population (50%) resides in the Governorate of Muscat and it is estimated that 78.5% of the Omani population live in urbanized areas(250). Oman has a mixed ethnic groups of Arabs, Baluchi (group of tribes also found in the Balochistan province of Pakistan as well as in neighbouring areas of Afghanistan),south Asians and Africans(250). Information on the nature of the health system in Oman will be further discussed in chapter 3 (p 54).

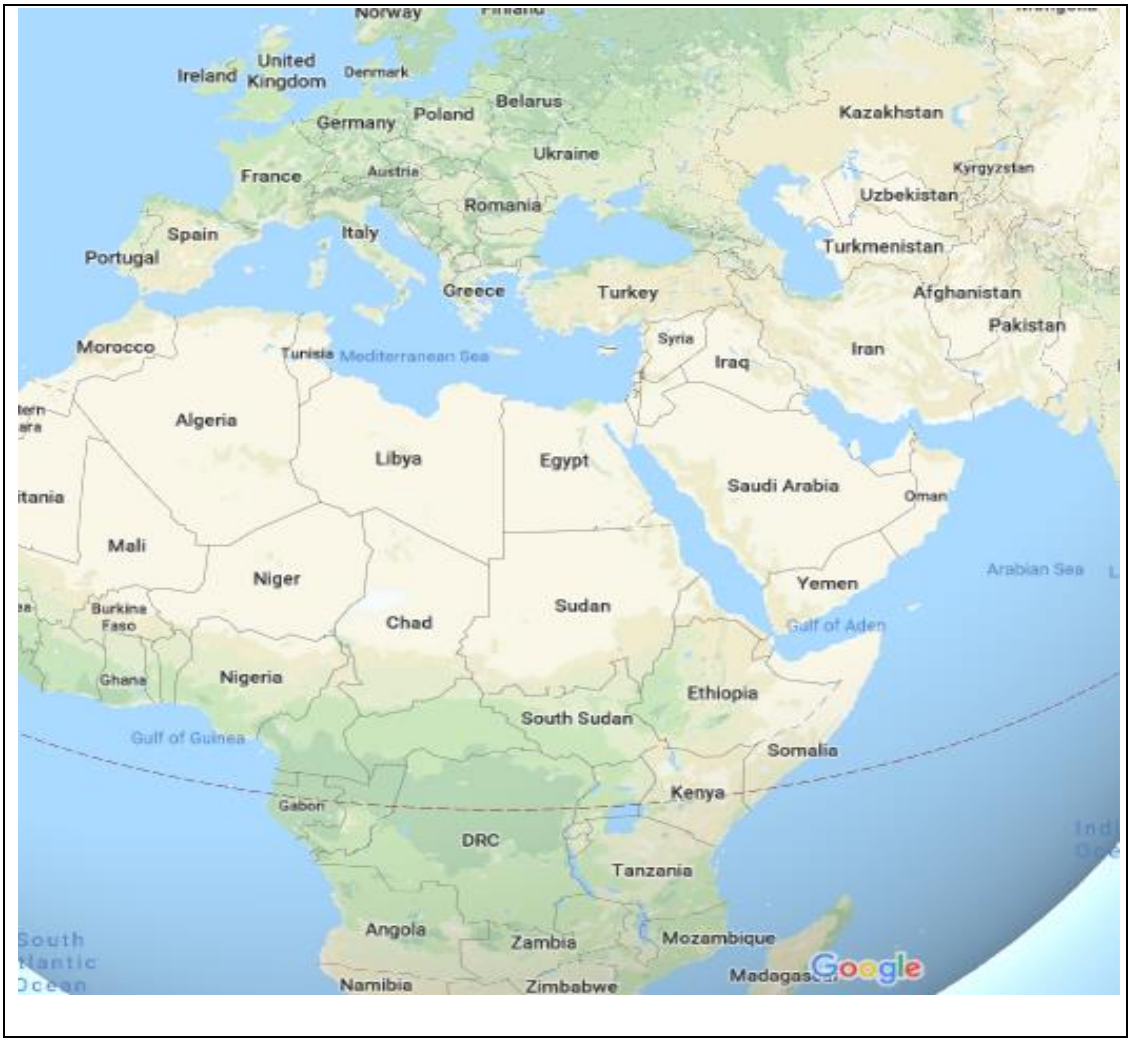


Figure 1.3: Map featuring the location of Oman in the Gulf

Source: Google maps (2018)(251)

1.8 Epidemiology of PCOS in Oman and the region

In Oman 74% of the population falls in the age group of 15-64 years and approximately 29% of women are of reproductive age - 15-49 years(249). However, the country specific prevalence of PCOS is still unknown. A recent study was carried out to estimate the prevalence of PCOS in Sultan Qaboos University Hospital (SQUH) (a tertiary teaching hospital located in the capital city Muscat)(252). This

was a retrospective cross sectional study using SQUH patient electronic records from the period of July 2006 to December 2010. A prevalence of 7% (255 out of 3644 Omani women attended the gynaecology clinic in SQUH in the same period) was identified(252). Another retrospective study of hospital records in Buraimi Hospital (in the North of Oman) reported a similar prevalence (7%, 251 out of 3,560 Omani women attended the gynaecology clinic during study period) of PCOS(253). These figures were retrieved retrospectively from hospital records which might have led to some cases to be missing due to either under-reporting of mild cases or failure to apply disease specific code to some of the clinically diagnosed cases. However, this reported prevalence of PCOS in Oman is similar to the reported worldwide prevalence(3).

Moreover, further studies have been conducted in Oman about PCOS including a case control study (2014) to assess the risk factors associated with PCOS among Omani women of reproductive age(254). This study found that obesity, and family histories of diabetes and PCOS were significantly associated with an increased risk of having PCOS among cases compared controls(254). Another cross sectional study (2015) was conducted to assess the level of awareness of PCOS among female university students. Overall 44% of the students had never heard of the term PCOS while 63% of those who had heard about it demonstrated a low level of knowledge. Friends were the most commonly reported source of information about PCOS among these students (57%)(254). These studies are non-published and mainly descriptive in nature carried out as university students' projects and lack proper methodological designs. Little is known about the reproductive health of women with PCOS in Oman.

No studies have been found on PCOS and its effect on women's reproductive health among the Middle-Eastern countries including Oman to be compared to those published on their European-American counterparts.

Regionally, a few other studies have estimated the prevalence of PCOS on a selective population of women and thus included small sample sizes. In addition, different diagnostic criteria were used which make results incomparable. In a study conducted among 102 women (Arabs and Asians) in a single hospital in the United Arab of Emirates (UAE) found 91% of them to fit the diagnosing criteria of PCOS(255). On the other hand, a study among 126 Qatari college females randomly selected, found 18.3% of them to have a diagnosis of PCOS according to NIH criteria(256). In a meta-analysis of 30 studies including a total of 19,226 Iranian women between years 2006-2011, reported a 19.5% (95 % CI: 2.24-8.14) prevalence of PCOS according to Rotterdam criteria(257).

Few other studies were conducted mainly to detect the prevalence of PCOS among women with symptoms of menstrual period irregularities and others with hirsutism. A hospital based study comprising 201 Saudi college females with symptoms of menstrual irregularities, hirsutism and acne, diagnosed 53.7% of them with PCOS based on pelvic ultrasound findings of their ovaries(19). In another study in Saudi Arabia among 101 women of fertile age and hirsutism, reported 82% to have PCOS; concluding PCOS to be the most common cause for hirsutism among women of reproductive age(258).

In Oman a recent case control (2017) study has reported the prevalence of depression, anxiety and stress among 52 women with PCOS compared to 62 PCOS-free women using Depression, Anxiety and Stress scale (DASS-21). This study reported an increased prevalence in all three psychological parameters among women with PCOS compared to controls with the highest being anxiety; however these differences in prevalence were found to be statistically insignificant(259). The study has also compared the prevalence of different sociodemographic and clinical symptoms of PCOS among the two groups including infertility and found a significantly higher prevalence of the latter among women with PCOS compared to controls(38.4% vs 13.3%,p=0.003)(259). However this estimate is descriptive of the sampled population and the prevalence of infertility among this groups of women with PCOS cannot be generalized as the study was not designed for this purpose.

1.9 Study rationale

Evidence suggests women from the Indian subcontinent and the Middle East are at a higher risk of developing GDM, PIH and preeclampsia compared to women from developed nations (260, 261). Moreover the estimated prevalence of PCOS in Asian countries is comparable to worldwide figures (144, 262). However, the available published data on PCOS and reproductive health outcomes refer mainly to Western populations and the majority were retrospective case control studies with poor study designs and small sample size. Furthermore evidence supports the influence of genetic and environmental factors on the phenotype of the syndrome, and ethnicity with a higher prevalence of PCOS symptoms among South Asian ethnic group of women compared to Caucasians (135, 263, 264). Under this scenario and considering the dearth of research done on PCOS in non-Western populations including Middle Eastern and Asian countries, this study will help shed more light on PCOS and the risk of metabolic, pregnancy and birth disorders during pregnancy among a representative sample of Omani pregnant women with PCOS. Moreover a cohort design was adopted and it followed clear criteria to identify cases with PCOS and controlled for some important confounders.

In addition, to the researcher's knowledge there is no previous qualitative study that has focused solely on the psychosocial effects of infertility among women with PCOS. Available qualitative studies have examined affected women's experience with PCOS symptoms in general. These women's experiences with infertility might be different to other women's experiences (due to other causes) in light of the dominant male like symptoms that are common among them that might compound their inability to conceive. Moreover the psychosocial impact of infertility

regardless of its cause is a neglected research area in the Arabic and Islamic region, where only a couple of qualitative studies were found in the literature. Therefore research tackling the psychosocial aspects of infertility is listed among the priority research areas by the ministry of health in Oman. In this context the cultural and contextual experience of infertility among women with PCOS is an important topic to explore in these countries.

Furthermore, there are expectations and immense pressure for women to get pregnant once they are married in the Arabic culture, which makes infertility an issue of huge concern. The social pressure and stigma associated with a woman's inability to conceive may push these women to seek medical care to achieve this goal. However, the extent to which their psychosocial wellbeing is being considered and supported is unclear including HCPs' views on the quality of care provided by them in fertility clinics.

1.10 Thesis General Aims and Objectives

1.10.1 Effects of PCOS on pregnant women and their newborns (quantitative study)

Objectives:

1. To determine the association between PCOS and selected metabolic outcomes namely, GDM, PIH and preeclampsia among Omani pregnant women.

2. To determine the association between PCOS and adverse birth outcomes among mothers and their newborns.

Primary outcomes: miscarriage, preterm delivery, stillbirths and undergoing C-section.

Secondary outcomes: macrosomia, LWGA, low APGAR score and admission to NICU.

1.10.2 The psychosocial effects of infertility among Omani women with PCOS and their satisfaction with healthcare services in fertility clinics (qualitative study)

The aim of this qualitative study was to understand the lived psychosocial experience of infertility among women with PCOS in the Omani society.

Objectives:

1. To explore the psychosocial effects of infertility among Omani women with PCOS.

2. To explore women's satisfaction with the healthcare services received in infertility clinics.

3. To explore the extent to which HCPs offer emotional support to women in fertility clinics.

1.10.3 Healthcare providers' perceptions of the care provided in fertility clinics (qualitative study)

This study aimed to gain insight into the quality of fertility care offered to infertile women with PCOS from HCPs' point of view and compare it to that from patients'.

Objectives:

1. Explore the gaps in fertility care from HCPs' perspectives.

2. Understand how HCPs approach and address infertile patients' emotional needs during medical consultations.

3. To propose recommendations for interventions or care guides for HCPs to enable them to better support infertile patients both physically and emotionally.

1.11 Value of the research

Findings will assist physicians to gain a better understanding of the true risks of PCOS on women's reproductive health compared to other risk factors and help them deliver health care based on risk assessment. In addition, results will help health organizations to better utilize available resources on early diagnostic and preventable measures. This will allow HCPs to effectively plan early preventive and diagnostic measures to avert the higher cost of the long-term more serious consequences of the disorder on both mothers and their offspring (145, 265-267). Furthermore this knowledge will enable physicians to provide appropriate, reassuring advice to affected women. On the other hand exploring the psychosocial experience among women with PCOS in the Omani society and their experience of health services received in infertility clinics, including the extent of emotional support offered will help identify how these women can be supported and thus improve healthcare delivery to this group in Oman. However taking it a step higher and further exploring HCPs' views on these aspects of care will allow to bridge the gap between patients and HCPs if it exists and thus recommendations can be made to satisfy and meet both groups' needs.

2 The philosophical approach underpinning the research methodology

2.1 Introduction

This chapter presents the philosophical views underpinning the research presented in this thesis. These will be discussed in relation to the mixed-methods approach utilised, with consideration of each method in turn.

A research paradigm or theoretical framework is defined as a *"Reflection of the researcher's beliefs about the world that s/he lives in and wants to live in. It constitutes the abstract beliefs and principles that shape how a researcher sees the world, and how s/he interprets and acts within that world"*((268), p262). These beliefs or worldviews guide research action or an investigation, including the research methods that will be used and how the data will be analysed(268). Epistemology is one of four elements of a research paradigm; ontology, theoretical perspective and methodology. Epistemology is concerned with the very bases of knowledge - its nature, and forms and how it can be acquired, and how it can be communicated to other human beings(269).

This research studied the impacts of PCOS on different reproductive outcomes among women in Oman. PCOS has hypothetically many negative effects on pregnant women (GDM, PIH and preeclamsia), on the pregnancy (miscarriage, preterm delivery, stillbirth and C-section), on the newborns (macrosomia, LWGA, low APGAR score and admission to NICU) and it is a common cause of infertility. Therefore, this thesis first, aimed to investigate the above mentioned metabolic,

adverse pregnancy and birth outcomes of the condition on pregnant women and their newborns. Furthermore as some women with PCOS fail to carry a pregnancy, this study also aimed to explore the psychosocial experience of infertility among affected women in the context of living in the Omani culture. Consequently, these women access fertility services and their perception of the quality of healthcare services in fertility clinics in Oman including the provision of emotional support was also explored. This exploration was important to be examined from both patients' and HCPs' perspectives as it is believed to provide a double faceted evaluation that would allow to bridge any gaps between receivers and providers.

Given the mentioned study objectives (listed in chapter 1, p 40), this thesis has opted to use the best approaches to gain knowledge and answer the research questions rather than being guided by a particular philosophical paradigm. Based on the research theory/question of each study, the researcher selected the research paradigm that can produce useful knowledge to be generalised or transferred into practice(270, 271). Therefore, the researcher opted to use a mixed-methods approach using both quantitative and qualitative study designs to answer the research questions. The epistemological background underpinning these designs and their relevance to the studies they are used for are further discussed in detail below.

2.1.1 Quantitative study

2.1.1.1 Positivist paradigm

Positivism is also referred to as the "*scientific method*" or "*science research*"(272). It aims to test a theory through "*observation and measurement in order to predict*

and control forces that surround us"((273),p 81). Therefore, it is used in research that tries to interpret observations based on measurable entities(274) and research following this paradigm is based on a deductive logic, where a hypothesis is formulated and then tested using mathematical calculations and equations to derive conclusions(275). This scientific method is used to study cause and effect relationships, and to do so the researcher needs to be able to control the potential impacts of explanatory factors on the dependent factors(276). The positivist paradigm assumes that context is not important and therefore the obtained results in one context should be applicable to other situations by deductive inferences(277).

The positivist paradigm underpinned the quantitative components comprising this thesis, to test the theory that pregnant women with PCOS are more likely to have a number of selected metabolic and adverse pregnancy outcomes (further mentioned and discussed in chapter 3, p 81) compared to women without the condition. Similarly, this paradigm was used to test the theory that newborns to mothers with PCOS are more likely to experience adverse birth outcomes (further mentioned and discussed in chapter 3, p 84) compared to newborns to mothers without the condition. These proposed theories look into cause-effect relationship between the independent factor (here PCOS) and the tested dependent outcomes in women and their newborns, which best fits under the positivist paradigm described above. It allowed the researcher to control for the other available and believed explanatory factors to prove the causality relationship between PCOS and the outcomes of interest.

2.1.2 Qualitative studies

2.1.2.1 Constructivist paradigm

Research informed by the constructivist approach seeks to understand the world of human experience implying that reality is socially constructed(278, 279) and it is not stable and different people have different accounts of the same phenomenon under study. Researchers following this paradigm rely upon the views of the participants in relation to phenomenon being studied, taking into account their background and experiences(279). It is the researcher's job to try to get into the heads of the subjects being studied to understand the meaning they attach to a phenomenon, in a given context. Therefore constructivists are more likely to rely on qualitative methods for data collections such as interviews(280). Unlike the positivist paradigm, research based on constructivist approach does not start with a theory, instead theory is inductively generated from the patterns and meanings obtained throughout the research process (281).

The second part of this research was underpinned by constructivism and thus qualitative methods as it focused on understanding the experiences of infertile women with PCOS living within the context of Omani culture and the meanings and interpretations related to the infertility within this culture. Furthermore it aimed to explore the experience of receiving and providing fertility services by women and HCPs respectively. This approach was best to answer these questions, given the current knowledge on these aspects being mainly obtained from the West and the extent of the transferability of the findings to the Middle East is unknown.

2.1.2.2 Reflexivity

Reflexivity is "*The continuous process of reflection by the researcher on his/her values, preconceptions, behaviour or presence on those of the participants, which can affect the interpretation of responses*"((282),p305). Reflexivity is one of the important elements in qualitative research to enhance validity and reliability. The process of reflection is achieved through the researcher attempting to understand how her/his own values and perceptions might have influenced their study design, data collection and interpretations of the phenomenon under study and thus adds credibility to qualitative data(283). Thus, rigorously engaging in this process and managing it correctly can ensure confirmability of study findings and that it is free from bias and prejudice.

2.1.2.2.1 "Reflexivity" implementation

Since the researcher in qualitative research is the primary "instrument" for data collection and analysis, reflexivity is deemed essential(284). Being reflexive is important to ensure validity of the obtained data and to avoid the researcher's preconceptions on the phenomenon under study to influence participants' responses or in the analysis of data.

Steps were taken by the researcher before engaging in this research to understand the different proposed methods to increase the trustworthiness of the obtained data and analysis process and to give the research credibility(285, 286).The literature suggests different ways of exercising reflexivity depending on the research question, researcher's position and the goal of the conducted

research(287). A reflexive diary was used in this study during the data collection process. This helped guide the interview process and maintained the researcher's curiosity to obtain more information from participants. The researcher had reflected on three main areas related to her own background where her own preconceptions and perspectives around the phenomenon under study might have potentially influenced the research process including; preparation of the interview guide, conducting the interviews or analysing the collected data. These are discussed in more details below

1) **Cultural background**

The absence of literature around the topic under investigation in the context of the Omani culture and the scant studies available from the neighbouring countries helped eliminate any solid perceptions, information and ideas around the topic. This allowed the researcher to have a more neutral mind-set approaching this topic. However, belonging to the same culture where the research was conducted, the researcher could not eliminate the preconceptions acquired living in this society. The researcher had the assumption that couples' relationships must have been threatened by the issue of infertility having heard stories within the community. However during analysis and by taking a more neutral attitude towards the obtained data, this idea was proved wrong, where most husbands were surprisingly supportive instead, even in where some of the women interviewed were the reason behind infertility (in this study due to PCOS). This reflects a shift in cultural norms as this support is common among the younger generations nowadays unlike before.

Moreover among the documented notes that was taken after the first couple of interviews with women with infertility the researcher wrote:

"I think there is a form of sensitivity in inquiring about husbands' role in a woman's journey with infertility. Possibly there are thoughts among these women about the interviewer being judgmental on their relationship with their husbands being from the same cultural background or about having touched an area that is already wounded by the issue of their infertility"

During the first couple of interviews, the researcher had feelings of interviewed women being uncomfortable to expose details of their marital relationship to a researcher who shares the same cultural background and who might be judgmental. This reflection helped the researcher better navigate around this area during the interview by rephrasing the inquiry and use of probes to get a more honest view from participants.

On the other hand there were some positive aspects of belonging to the same culture to that of the participants. The researcher was able to better understand patients' suffering and to make sense of their experience that allowed her to be more accurate in transferring it to meaningful themes.

Experts recommend that by making field notes or memos, researchers are able to acknowledge ideas that they may not have been aware of (288). By embarking on this process and having personal interest in the topic, the researcher was encouraged to think about getting started with the project and interviewing participants. Therefore she conducted a pilot study with a fertility patient who is also her cousin and it aroused her desire to know more about certain aspects of the experience of infertility in her own community; one of them was the topic of adoption which the interviewee brought up during the discussion being an adoptive

mother herself and an advocate for it in the community and thus helped in modifying the interview guide.

The writing of field notes continued throughout the collection of interview data. The researcher learned the areas that should be investigated in more depth and how to set aside any previous knowledge about what is being inquired. The researcher also learned to step back to attentively listen to the experience of the informants. As Maxwell asserts that field notes "*convert thought into a form that allows examination and further manipulation*"((289),p94).

2) Fertility status

Despite the researcher being familiar with the culture where the research is being conducted, she does not belong to this group of women being a healthy fertile woman and a mother of two. This helped eliminate any personal views that could have influenced the research process and helped data to be mainly from the informants about their experience living with infertility and their views regarding the notion of adoption. Among the documented notes around this, the researcher noted:

"It was interesting to learn the level of suffering these women go through in the community just because they cannot bear a child and it was also interesting to know that most of them are willing to take up the option of adoption but it was surprising to find most of them share similar concerns and worries mainly due to community's rejection for adoption"

3) Medical background

The researcher is a medical doctor by profession and this has influenced the interviews conducted with both patients and HCPs. Women perceived the researcher as a highly professional person, as Omani patients in general place a high value on the medical profession. This allowed them to build trust with the researcher (interviewer) and open up freely about their experience and narrate their feelings and sufferings knowing it will be evaluated properly. Many women expressed how comfortable they felt after the interview having the chance to vent their feelings to someone outside their social circle and not feeling guilty or vulnerable about their confessions. The researcher noted in her reflexive diary:

"I was pleased to sense how honest the interviewees were talking about their experience and how I was able to gain their trust to confess about things that they admitted not to have shared with anyone before. An interviewee today shared how she had to lie to convince her husband to leave his parents' house and live in a house of their own mainly to escape their constant pressure and questioning about their fertility issue and this was the first time for her to share this information with anyone"

Furthermore, as the researcher is a trained doctor herself (family physician), it was important to reflect on other HCPs' responses to the interviews, wondering whether the obtained responses were honest or biased with the assumption that HCPs are trying to overestimate their performance. This helped the researcher to be more cautious about this point during data collection and interpretation. A pilot study was carried with a fertility HCP and the researcher sensed the possibility of

HCPs trying to overestimate their attitude when it comes to providing emotional support to fertility patients. Thus the interview guide has been modified following the pilot study where a question has been added to those who admit to provide emotional support to their patients by asking them to narrate an incidence where this has been implied. Few of those who admitted to provide emotional support failed to demonstrate it in practical terms when they were asked to.

Field notes were used along with the transcribed interviews to examine the informed experiences of participants and formulate the generation of themes, before these were compared and agreed with those identified by another independent qualitative researcher (academic supervisor).

2.1.2.3 Trustworthiness of collected data in qualitative research

According to the constructivist/interpretivist paradigm the extent to which data and data analysis are believable, trustworthy and authentic are indicators of their credibility(290). To achieve this, qualitative researchers are advised to minimize bias and present data as they emerge from participants' experience as much as possible. Of the common proposed ways to help put aside researcher's own values and thoughts from the phenomenon under study is "bracketing". Bracketing is defined as a *"Methodological device that requires deliberate putting aside one's own belief about the phenomenon under investigation or what one already knows about the subject prior to and throughout the investigation"* ((291),p 138).

Although bracketing is mainly a feature in phenomenological research, it has also been proposed to be practised in other types of qualitative studies(292). The

researcher opted to practice bracketing as well in this research to increase the trustworthiness of the study findings.

Different strategies were proposed by Hamill and Sinclair to help researcher's to implement "bracketing"(293). Among these is to delay conducting a literature review until after data collection and analysis. However, in practice, the absence of the knowledge-gap and therefore the justification for the proposal to conduct the research might be challenged(293). Most of the up to date published qualitative research on the psychosocial experience of infertility focuses on patients' and HCPs' views on fertility services are from developed or developing countries. Very scant studies included those from the Middle East region and nothing is found from Oman. Therefore, the experience on the above mentioned aspects in the Omani society is not known. This helped to minimize the effects of any prior thoughts around this topic with the same context where it had been studied.

The second strategy is to use "reflexivity" which was practised and described above. The third followed strategy was conducting a face to face interview, which allowed a deeper understanding of participants' lived experience(294). The manner of asking the questions by the researcher led the conversation in a way to get rich data based on participants' responses. Moreover using a semi-structured interview guide was a good tool that allowed the researcher to follow the cues offered by the participants(295), who led the conversation minimizing the researcher's preconceptions influencing the covered topics during the interviews. The researcher also used probes around interesting areas arising from participants(296), to get a better understanding of participants' lived experiences.

2.1.2.4 Methodological considerations in qualitative research

In the positivist paradigm sample size needs to be calculated taking into account the prevalence of outcome measures of interest, similar studies conducted in the region and the size of baseline population where results can be generalized back to. This was followed to calculate the sample size required for the quantitative aspects of this research (see chapter 3, section: power calculation, p 64). However, sample size is of less importance in qualitative research.

In qualitative research sample size is mainly dependent on the richness of the obtained data, where the main aim is to get an understanding and an account of individuals' lived experiences(297). Therefore, in qualitative research quality outweighs quantity. Furthermore researchers are currently advised to use their own judgment to choose the sample size for their qualitative research based on the following criteria: the scope of the study and what objectives it needs to cover, the nature of the topic if obvious, clear and how easily information can be obtained from topics that are under the surface(298), the quality of the obtained data to reach saturation (obtaining a comprehensive understanding by continuing to sample until no new substantive information is acquired(299)) and finally the design followed to conduct the research and the tool used for data collection(300). For these studies, the researcher decided on the appropriate sample size taking into account such guidance.

To meet the objectives of the qualitative studies in this research, two fertility clinics were chosen to select participants as they are the only clinics offering fertility

services under the government sector in Muscat. To obtain data for the qualitative studies, the researcher opted to use face to face semi-structured interviews, as this is a flexible tool and was considered the most appropriate to get the most accurate information out of interviewees on a given topic(297) . This tool allowed the interviewer to be prepared for the interview, to cover certain aspects during the interview yet be able to follow topical trajectories in the conversation that may stray from the guide as appropriate. Following, this method allows to analyse the topic in a more inductive than a deductive approach(301) . Sampling participants for the studies was based on purposive sampling. This sampling method for qualitative inquiry is generally assumed to yield cases that are “information rich”(302). It also involves selecting participants that are considered to be knowledgeable about the phenomenon under study(303), but also available and willing to participate and able to articulate their experiences openly(304) . Considering the above mentioned methodological approaches, and given that previous studies which have used similar methodological approaches to cover these topics sampled between 10 to 25 participants(305-310), the researcher opted to interview a total of 20 women with infertility and 20 HCPs in fertility clinics across the study hospitals. Furthermore, in selecting the sample size the researcher also accounted for the feasibility of completing these studies, within the available resources and timeframe. However, it is worth noting that sampling remained flexible depending on data saturation being assessed continually.

3 Quantitative study primary data collection and creation of study database

3.1 Study settings

The Ministry of Health (MOH) is the main provider of health services in Oman. It has achieved impressive progress since 1970 when the reign of his Majesty Sultan Qaboos laid a clear plan to build the country's healthcare infrastructure. Healthcare in Oman was very limited before 1970,when only two hospitals existed: one was called the Knox Memorial hospital and opened in 1935 by the American Arabian Mission while the other was created in 1948 and was supported by the Sultan at that time ,however it was administered and staffed by the British consulate(311). Access to healthcare services was very difficult. While hundreds of people were waiting to see one of the 13 foreign physicians who served the whole nation, others were travelling for days to reach to them and wait for their turn to be seen(312). The mortality rate was very high: one out of every 8 live born infants died before completing their first year while one out of every five died before the age of 5 years(313). The morbidity rate was also high, especially for infectious diseases: one out of every three people had malaria and out of one thousand people, 30 suffered from trachoma, 8 from pulmonary tuberculosis and 6 with hepatitis. Life expectancy was estimated to be just 49.3 years(313).

Since 1970 efforts were made to make healthcare access almost universal and free to all Omani citizens(2). These achievements are evidenced through the high level of achieved health indicators that are comparable to those of developed countries(312). As per the annual Oman's health report of 2016, the death rate of

every 1000 infants decreased to 9.2 and 11.7 for every 1000 children below the age of 5 years. Moreover Oman has achieved 99.9% immunization coverage for children against infectious diseases namely tuberculosis ,polio and measles(314). Life expectancy at birth was reported to be 75.7 years(314). Table (3.3) summarises Oman's health indicators in 2016 compared to before 1970.

Table 3.3: Progress in Oman's health indicators in year 2016 to before 1970

Health and service indicators	**Before 1970+**	**2016***
No. of hospitals	2	55 (government sector)
No. of doctors	13	6,873 (government sector)
Infant death rate	1 in every 8	9.3 per 1000 live births
Child death rate	1 in every 5	11 per 1000 live births
Immunization coverage	N/A	99.9%
Major causes of death	communicable diseases	Non-communicable diseases
Life expectancy	49.3 years	75.7 years

+Source: Oman annual health report 1978((313)

***Source: Oman annual health report(314)**

Oman's remarkable achievements in health over a short span of time helped it get both regional and international recognition. In the year 2010 Oman's healthcare system was ranked the 8th in the world by WHO, outperforming developed countries such the United States, Canada, Japan, Norway and the United Kingdom. In addition it was ranked by WHO in the same year as the top system for cost-effectiveness(315).

Government expenditure on health in Oman accounts for 82.5% of total health expenditure while the remaining is contributed by the private sector. The government is responsible for providing 93% and 97.3% of hospitals and hospital beds nationally respectively(314). Nowadays the government owns a total of 55 hospitals (3).

In Oman, healthcare is delivered through institutions at different levels (primary, secondary and tertiary), which are linked via a chain of referral systems. Primary healthcare is considered the first point of access to healthcare. It consists of health centres (HCs) that are widely distributed across the country and easily accessible to individuals and families. Nowadays more than 98% of the Omani population have access to primary care and the remaining 2% are reached out to in remote mountainous areas through mobile medical teams(316).

Access to the national healthcare system in Oman requires an annual purchase of a "health card" (cost 1 Omani Rial (OR) = £1.96) and co-payment for each visit (0.2 OR = £0.39), this amount is unified across the citizens regardless of age, gender and medical condition. This fee is believed to be affordable to majority of the Omani population except for 21.9% of families with low income who are exempted from payment(314). The primary HCs provide preventive, curative and promotive primary healthcare to the community(5). This includes antenatal care (ANC), postnatal care (PNC) and birth spacing services for women attending these centres.

The second level of healthcare is delivered to people through regional and sub-regional hospitals. These centres are fully equipped and provide services in different medical specialties including internal medicine, paediatrics, surgery,

accident and emergency and obstetrics and gynaecology(2). Patients from these regions who require specialized care are referred from primary to secondary care in their regions through a well-established referral system.

Specialized care for cases in different medical specialities such as oncology, cardiology, obstetrics and gynaecology and others that require specialist care is delivered to the population through the tertiary hospitals. Four of these hospitals act as national referral tertiary hospitals, are located in the capital city Muscat and provide general acute care (The Royal hospital, Khoula hospital, AlNahdha hospital and Sultan Qaboos University hospital). In addition patients with complicated conditions that are beyond the management capability of the regional secondary care are referred by their treating physicians to these tertiary centres in Muscat(6).

Special emphasis has been given to the private sector by the government to help decrease the burden on the public sector. The government continues to provide the required financial and technical support to private hospitals and clinics to encourage and enable them to invest in the healthcare sector. Health services in the private sector are available for Omani citizens and expatriates through out of pocket payment or are financially supported for some government-employed staff and their families who receive free healthcare services(312). The private sector is left to cover the pharmaceutical sector and a significantly large proportion of dentistry services(312).

Advanced maternal services in obstetrics, gynaecology and infertility are provided in three out of the four national tertiary centres in Muscat, namely The Royal hospital (RH), Sultan Qaboos University hospital (SQUH) and Khoula hospital. Both

normal and complicated pregnancies among women residing in the capital city Muscat will end in these tertiary hospitals. While only complicated obstetrics and gynaecological cases among women residing outside the city Muscat will be referred to them if they cannot be handled by their regional hospitals. This study was carried out in RH and SQUH. These two hospitals follow the Rotterdam diagnostic criteria to identify women with PCOS. Khoula hospital is not included due to the discrepancy in the criteria used to diagnose the condition, where both NIH and Rotterdam criteria are implemented to diagnose cases with PCOS. Although SQUH is located in the capital city Muscat, cases from other regions are referred here, as hospitals in these regions lack advanced gynaecological care. However, priority for treatment in SQUH is for university and hospital staff and their families, and access is therefore considered more restricted. On the other hand, the RH is a more public tertiary centre and it enjoys maximum autonomy in MOH as it is one of the national tertiary centres that provides medical services in all major medical specialities. It provides services to people from a wider catchment area and accepts country-wide referrals, therefore a larger pool of cases for the study was expected in RH compared to SQUH. Most women access these hospitals easily using their own private vehicles as it is the norm in the country where the majority of citizens own cars. The proportion of car ownership was estimated to be 90% among Omani population according to the 2010 census(315). Public transportation has recently been implemented in the capital city Muscat and it connects to nearby regions around the city. Currently it is mainly being used by expatriates as it costs less than rental cars (taxis).

3.1.1 The nature of antenatal care in Oman

In Oman, women with low risk pregnancies will normally have a total of 5 antenatal visits (Table 3.4). Pregnant women all over the country usually seek medical care from ANC clinics at their local primary HCs early during their pregnancy (4-12 weeks of gestation). Women with low risk and uncomplicated pregnancies living outside the capital city continue to be followed up in their local HCs until 28-30 weeks gestation, then they get referred to the designated secondary care centre for their last follow up appointment and delivery. Pregnancies with high risks or complications are referred earlier to the tertiary centres in Muscat for follow up and care if regional hospitals lack the required experience or the set up to handle these cases. All low risk pregnant women living in the capital city Muscat get referred at 28-30 weeks of gestation from their local HCs to the designated tertiary centre for their late pregnancy follow ups and delivery. The high risk pregnancies instead get referred earlier, as Muscat city lacks secondary care centres with specialized delivery services as these are provided by the existing major tertiary centres in the city.

Table 3.4: Antenatal visits for pregnant women in Oman

When	Tasks
At booking	• Profiling • A leaflet explaining all the services provided during this visit including: medical & obstetrical history, laboratory tests, clinical examination, risk grading, ultrasound for dating and health education will be provided. • History taking • Clinical examinations; breast, systemic, weight, height, BMI, BP and fundal height. • Laboratory tests: Urine tests (for albumin, ketones, glucose, and culture), CBC, Blood group & Rh, RBS/FBS/HBA1C, OGTT (if indicated), Antenatal screen (VDRL/RPR, HIV, HBSAg, Rubella), Abs test (if Rh-ve), HB variant analysis and G6PD (if not known) • Ultrasound for viability and dating • TT vaccination (if indicated) • Risk grading • Supplementation of folic acid. • Counsel on: warning signs, exposure to X-Rays & teratogenic substance , clinic attendance, nutritional advice, information on pregnancy signs and symptoms
12-14 weeks	• Clinical examinations : BP • Laboratory tests: Urine dipstick (for albumin , ketones, glucose) • TT vaccination (if indicated) • Risk grading • Supplementation of prenatal vitamins, folic acid and iron if Hb <10 g/dL or multiple pregnancy • Counsel on : Danger signs , diet and supplementation
22-24 weeks	• Clinical examinations: BP, fundal height, fetal heart sounds, asses fetal movement • Laboratory tests: Urine dipstick (for albumin , ketones, glucose), OGTT (24-28 wks) • Risk grading • Supplementation of folic acid & iron • Counsel on: warning signs, diet, exercise, compliance of iron and managing common symptoms
28-30 weeks	• Clinical examinations: BP, fundal height, fetal heart sounds, asses fetal movement • Laboratory tests: CBC, Urine dipstick (for albumin , ketones, glucose), ABS test (if indicated) • Risk grading • Supplementation of folic acid & iron • Counsel on: warning signs, preparation for lactation, fetal movement. •Give a referral letter to get an appointment at 36-38 weeks in the ANC clinic at SQUH.
32-34 weeks	• Clinical examinations: BP, fundal height, fetal heart sounds, asses fetal movement. • Laboratory tests: Urine dipstick (for albumin , ketones, glucose) • Risk grading • Supplementation of folic acid & iron. • Counsel on: warning signs, preparing for delivery including place for delivery, signs of onset of labor.

Source: Quality manual of the department of obstetrics and gynaecology (SQUH)

3.1.2 Maternal and antenatal healthcare services in Oman

Maternal and child health services have been uniformly implemented in Oman at a national level since 1987(317). Once a woman is found to be pregnant, she gets registered in the local HC assigned to her catchment area. A maternal health card "MHC" is then issued for her which includes the following ten sections; socio-demographic information of the mother, risk factors at beginning of pregnancy, past medical history of the mother and her family, obstetric history, gynaecological history, contraceptive use, clinical findings at the time of antenatal care visits, results of blood and ultrasound images, details of delivery, and details of post-natal visit. This card is filled out by medical staff (both physicians and nurses) during woman's visits to antenatal clinics located in these HCs. Those women continue to use this card postnatally in order to receive post-natal services including birth spacing. Oman has achieved 99% of ANC coverage in 2016, while ANC visit in first trimester was achieved by 67.9% of the population(314). In 2016 74.5% of pregnant women had at least 4 ANC visits during pregnancy(314), while 65.9% of women had been assessed at least once during their last 4 weeks of pregnancy. Only 0.5% of mothers have never visited ANC during their pregnancy. During the same year 19.4% of all deliveries were made through C- section, where elective C-sections constituted 33.5% of all C-sections(314).

Miscarriage most often ends up in the hospital's accident and emergency department (A&E) and its management depends largely on the type of miscarriage. Complete miscarriages (when the embryo or products of conception have emptied out of the uterus) will most likely be managed in A&E and patient will be given a

follow up appointment in the obstetrics and gynaecology outpatient department. While incomplete miscarriages and ectopic pregnancies will require hospital admission for close monitoring and medical/surgical intervention.

After delivery, each newborn receives a child health card “CHC”, which is a registry of his/her health events since delivery until 6 years of age. The CHC includes the following six sections: socio-demographic information about the parents, risk factors at time of delivery, details of delivery, vaccination schedule, growth charts, developmental milestones, and details of each visit to the hospital.

This chapter will now continue to describe the study population, sample size calculation, exposed and unexposed groups selection criteria and the creation of study’s database**.**

3.2 Study design

This study adopted a positivist approach and followed a cohort design (see chapter 2 for methodological justification, p 51). The exposed group was Omani pregnant women with a diagnosis of PCOS and the unexposed group was Omani pregnant women without PCOS.

3.3 Study population

The study included all pregnancies (spontaneous or assisted conception) in women with PCOS and women without PCOS recorded within a time period from 2006 until 2017 (inclusive) in two tertiary hospitals located in the capital city of Oman

(Muscat): SQUH and RH. Inclusion and exclusion criteria for exposed group selection are listed in table (3.5).The selection of pregnant women without PCOS as an unexposed group in this cohort was the most appropriate. As this study aimed to examine the effects of PCOS as an exposure on both pregnant women and their newborns. The unexposed group were selected based on the same criteria to those for the exposed group with the only difference being the absence of PCOS diagnosis. The inclusion criteria for cases and controls included Omani pregnant women in the reproductive age group of 18-49 years old who have attended the same two study hospitals for their pregnancy follow up and pregnancy outcome with the only difference being the presence of PCOS among cases and its absence among controls. These inclusion criteria insured matching the cases and controls as much as possible in their geographical, ethnic, age and social backgrounds as well as the level of medical service received being both followed up in the same study hospitals during their pregnancy. Similarly for the exclusion criteria, both groups were first selected based on the absence of the outcomes of interest under examination in this study including DM and HTN. In addition, the common and known medical conditions (listed in table 3.5) to affect the other outcomes of interest in this study namely miscarriage, stillbirth, preterm delivery and delivery by C-section were excluded among both cases and controls as it was thought to allow a more direct attribution of the study findings to the entity of PCOS and restrict confounder analysis to the demographic and obstetrics characteristics of participants. Moreover cases and controls with loss of follow up were also excluded from the sample to reduce the amount of missing data on outcomes of interest. Although this might have introduced selection bias to the study's sample, this is

unlikely given the non-rare nature of the exposure status under study (here PCOS) and the wide catchment area of study hospitals that allowed for a diverse sample of cases and controls.

Table 3.5: Inclusion and exclusion criteria for exposed group selection

Inclusion criteria	**Exclusion criteria**
• Omani • Aged between 18-49 years at any stage of pregnancy • Pregnant regardless of gestational age • Cases with PCOS should be diagnosed according to Rotterdam criteria (using PCOS specific ICD codes) • Attended SQUH or RH for antenatal follow up and delivery or pregnancy outcome (miscarriage, ectopic or stillbirth) • With spontaneous or assisted conception • Singleton or multiple gestations	• The presence of diabetes mellitus diagnosis prior to pregnancy as it will mask the studied outcome “gestational diabetes(GDM)” • The presence of hypertension prior to pregnancy as it will mask the studied outcome “pregnancy induced hypertension(PIH)” and “preeclampsia” • Other pregnancy affecting disorders diagnosed prior or during pregnancy such as : systematic lupus erythematosus(SLE), uterine fibroids, reproductive organs tumours and disorders, cancer, thyroid disorders, serious heart diseases, psychosis • Loss of follow up(defined as no medical information available for a pregnancy outcome after patient have had ANC visits in one of study hospitals due to travel, movement to another city outside the hospital’s catchment area or continued

	following up in private hospitals) • Unlabelled cases(Patients with clinical symptoms and signs of PCOS according to physicians' clinical notes but no ICD code of PCOS is assigned to them in the medical health records) • Infertility(Patients with PCOS and primary infertility as this study aims to examine pregnancy outcomes among women with PCOS)

3.3.1 Power calculation

It was estimated that data will be available for at least 500 pregnant women with PCOS across the two centres, and extracting data on these women plus 500 pregnant women without PCOS is thought to be achievable within the available time frame.

We computed the minimum prevalence of each outcome detectable in women with PCOS compared to controls based on a sample size of 1000 (equal groups), a two-sided significance level of 5% and power of 80%. Details are shown in table (3.6)

These represent best-case estimates; in practice there is likely to be significant clustering of outcomes within the data (due to multiple pregnancies among the same women, and multiple offspring within some pregnancies). It is not possible to estimate the impact of these effects upfront without knowing the intracluster correlation for each outcome, therefore an additional power analysis is included with the comparative results in the following chapter (chapter4, p 110)

Table 3.6: Basis of sample size calculation

Outcome	Prevalence in women without PCOS (%)	Minimum prevalence detectable in women with PCOS (%)
GDM	10.0	16.0
PIH	6.0	10.9
Miscarriage	3.0	6.8
Caesarean section	12.0	18.4
NICU admission	5.0	9.6

3.4 Data source

The main source of data was patients' electronic hospital records. The two hospitals use two different software programs (TrackCare in SQUH and AL-Shifaa in RH) to store patient's information (Appendix B1&2: screen shots of various sections of the health information systems of study hospitals). The programs allow healthcare providers in the obstetrics and gynaecology department to record patients' demographic information, current and previous pregnancies' details, vital measurements for each visit, follow up visits' outcomes, procedures, medications, blood results, delivery ward or theatre notes, post-delivery recovery notes and discharge notes. Moreover it displays patients' visits to any other clinic along with any performed procedure and blood test results (Appendix B1&2).

3.5 Case identification

Both study centres use ICD-10 codes(318) to classify medical diseases. The ICD-10 codes used for PCOS were "E28.2" Poly cystic ovarian syndrome (PCOS) and "E282"Poly cystic ovarian disease (PCOD)(318), and these were used in conjunction

with the ICD codes for pregnancy and delivery (O00-O08 and O80-O84)(318) (Appendix C: list of the used pregnancy and delivery related codes) to identify cases of pregnant women with PCOS. Physicians are the only healthcare providers authorized to record patients' medical information during their visit to the outpatient department or during hospital admission including; disease signs and symptoms, past medical history, family history, clinical examination findings and ultimately the differential diagnosis. Moreover, physicians can order the required medical tests and radiological imaging through the system. Healthcare information about patients has been directly recorded on computers by physicians since 2000, while previously it was only documented on paper records. Since the implementation of ICD code system, physicians have been required to assign appropriate ICD codes for each patient for the different diagnoses. This code is disease specific and it is given only after a complete assessment of the patient's condition. It is assigned to the patient once the diagnosis of a disease is confirmed, whether this is during patient's hospital admission or during their outpatient visits. This code will appear under a specific tab (Appendix B1&2) on patient's hospital health record and will be visible to all healthcare providers from different specialities. Although medical information is documented only by physicians, it is nurses' task to record into the system patients' vital signs for each visit. This includes their physical measurements (blood pressure reading, weight, height and BMI), as patients get these measured in the triage room by nurses before they see the physician in an outpatient department or during hospital admission.

In addition, each hospital has a medical records department with assigned professional coders, grouped by different medical specialities. Their task is to go through patients' notes to double check the disease codes entered by physicians using the latest ICD-10 disease code manually and to assign codes to those with missing entries. Although disease classification using ICD-10 codes was adopted in the year 2000 in RH, it was not until 2006 where labelling cases using ICD codes was mandatory, whereas in SQUH ICD codes were adopted in 2006 and has been implemented since then.

Cases of PCOS were retrieved from the period between 1st January 2006 until 31st May 2017, in both study hospitals. Implementing the exclusion criteria mentioned in table (3.5), a total of 305 eligible pregnant women with PCOS across the two hospitals were included in the study out of a total of 638 married women labelled with PCOS across the two study hospitals. Figure (3.4) shows a diagram of study population recruitment.

3.6 Selection of unexposed group

The unexposed group was recruited from the health records of the same two tertiary hospitals recorded during the same period of time (between 1st January 2006 until 31st May 2017). They were selected to be comparable to the exposed group in hospital of delivery and nationality (all Omani). Implementing the exclusion criteria mentioned in table (3.5), a total of 617 eligible pregnant women without PCOS across the two hospitals were selected as an unexposed group out of a randomly selected list of 845 pregnant women without PCOS withdrawn from a list

of 143,323 pregnant women who visited the two study hospital during the same time period (Figure 3.4).

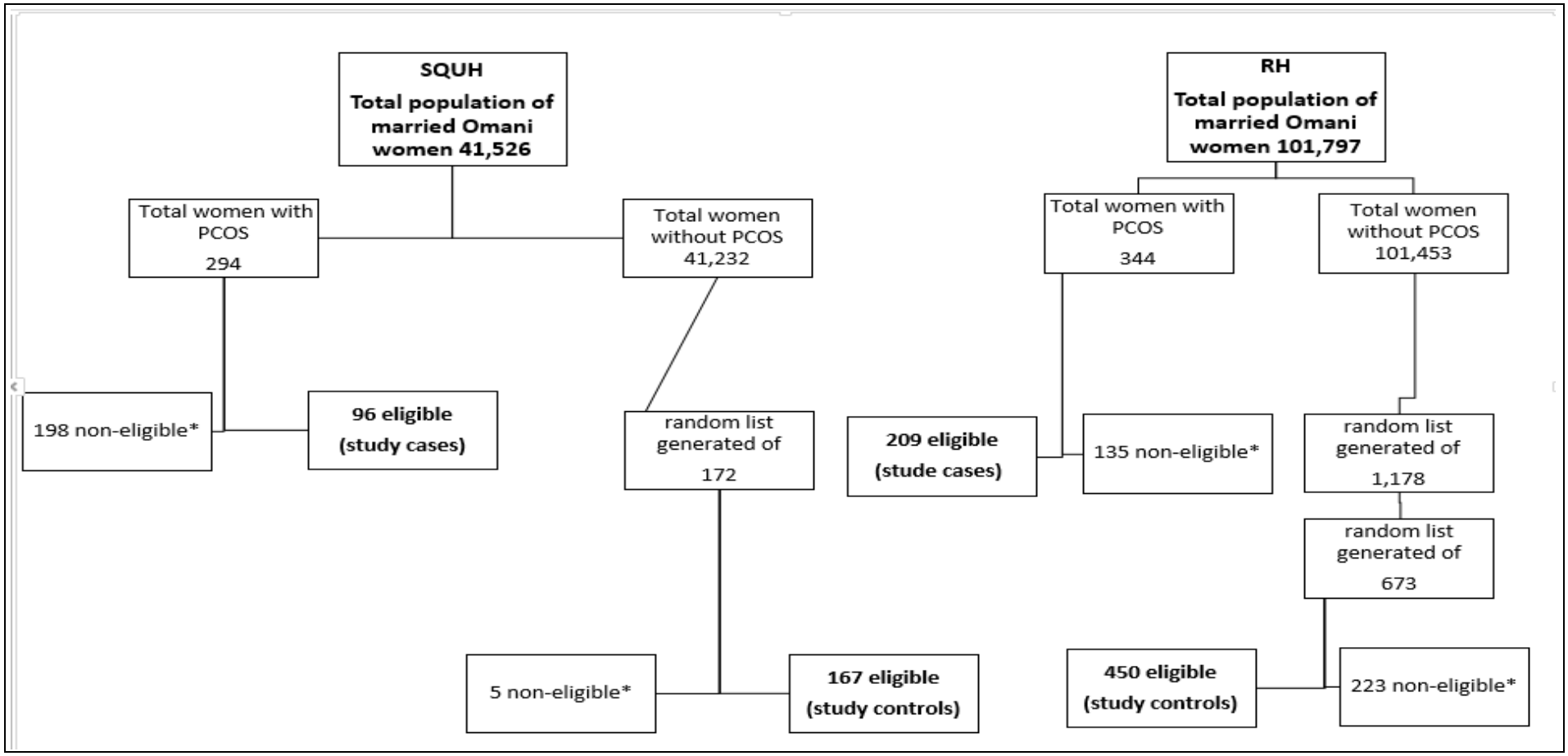


Figure 3.4: Flowchart of study population recruitment within the study time period

***Check table (3.3) for exclusion criteri**

3.7 Pilot study

A pilot study prior to full data collection was performed with the health records of the study hospitals. Among the lists of eligible pregnant women with PCOS and the eligible pregnant women without PCOS identified over the period between January 2006 until May 2017, 100 were randomly selected across the two hospitals (50 participants from SQUH and 50 participants from RH) for data extraction using the created STATA spreadsheet. The main purpose of this pilot study was to estimate the time required for data extraction using participants' health records, given that the researcher had to go through each participant's pregnancy follow up visits' notes and admission notes in order to create the final study dataset. Moreover, it aimed to check the availability and completeness of the required data for both exposed and unexposed groups. The data extraction process from electronic health records took an average of 20 minutes per participant and it was believed that data collection on an estimated total sample size of 1000 women was feasible given the study's data collection period. In addition, the availability and completeness of data required by the study was satisfactory to meet the study's objectives. Furthermore few variables were decided to be added to the data spread sheet to potentially enrich the analysis namely participant's weight recordings at different gestational age as per their availability, as not all participants had their weight recorded early during pregnancy. Moreover in order to carry out a sensitivity analysis, indicator variables for the diagnosis of PCOS and its exclusion were created to be implied on the entire participants in the dataset in order to detect classification bias among cases and controls.

3.8 Data collection and management

Following the pilot study, data were fully extracted by the researcher from participants' electronic hospital records. The medical record department of each study hospital generated a list of medical record identification numbers (MRN) of eligible participants using the appropriate ICD codes provided by the researcher.

Database variables included participant's demographics, characteristics and outcomes of interest (Appendix D shows the full list of variables dictionary including variable name, type and measuring unit). Participants were identified in the dataset by their MRNs. These numbers were repeated more than once in the pregnancy dataset if participants had more than one pregnancy in the study's hospital. In the children dataset, live-borns from the same pregnancy or from the same mother had also the same MRN. The two study hospitals use different MRN systems for patients therefore overlap of participants' medical numbers from the two hospitals was not possible.

3.8.1 Data categorization

Data were first managed by categorizing the required variables namely hospital name, age, residence, educational level, employment status, conceiving method, number of gestations and participant's parity and gravidity status. Other variables were left as continuous variables including participant's weight measurements, height, weeks of gestation at pregnancy outcome and neonate's birth weight. Table

(3.7) demonstrates selected categorical and continuous variables from the dataset.

A complete variable dictionary can be found in Appendix (D).

Table 3.7: Selected dataset variables, demonstrating some categorical and continuous variables

Variable name	Variable label	Variable description	Variable type	Variable categories	Variable unit
hospitalname	Hospital name	Name of study hospital	categorical	SQUH RH	
agecat	Age category	Participant's age category	categorical	15-20years 20-25years 25-30years 30-35years 35-40years >=40years	year
residence_cat	Residence category	Type of participant's residence area	categorical	Rural Urban	
edu_level	Educational level	Participant's educational level	categorical	Primary or less Secondary University or college	
employment	Employment status	Participant's employment status	categorical	No Yes	
gravida_cat	Gravida category	Category of participant's gravidity	categorical	1 2 3 >=4	
para_cat	Para category	Category of participant's parity	categorical	1 2 3 >=4	
PCOS_status	PCOS status	Participant's diagnosis of PCOS	categorical	No Yes	
conception_ mode	Mode of conception	Participant's conceiving method	categorical	Natural Metformin Clomid IUI IVF	
No_of_foetus_cat	Number of foetus category	Category for number of	categorical	1 2 >=3	

		foetus in a pregnancy			
Weight x	Weight x recording	Participant's x weight	continuous		kg
Height	height	Participant's height	continuous		cm
delivery_mode	Delivery mode	Mode of delivery	categorical	Natural Assisted Elective c-section Emergency c-section	

3.8.2 Date variables

Date of last menstrual period (LMP i.e. start of pregnancy date) was calculated using the formula: (date of pregnancy outcome – (weeks of gestation at pregnancy outcome x 7). To estimate the gestational age at each time participant's weight was recorded, the researcher documented in the dataset the dates of weight measurements for each pregnancy and then used the following formula to calculate the above date: (date of weight recording – date of LMP)/7. Therefore multiple gestational age were calculated and generated as per the number of weight recording episodes in each pregnancy for each participant.

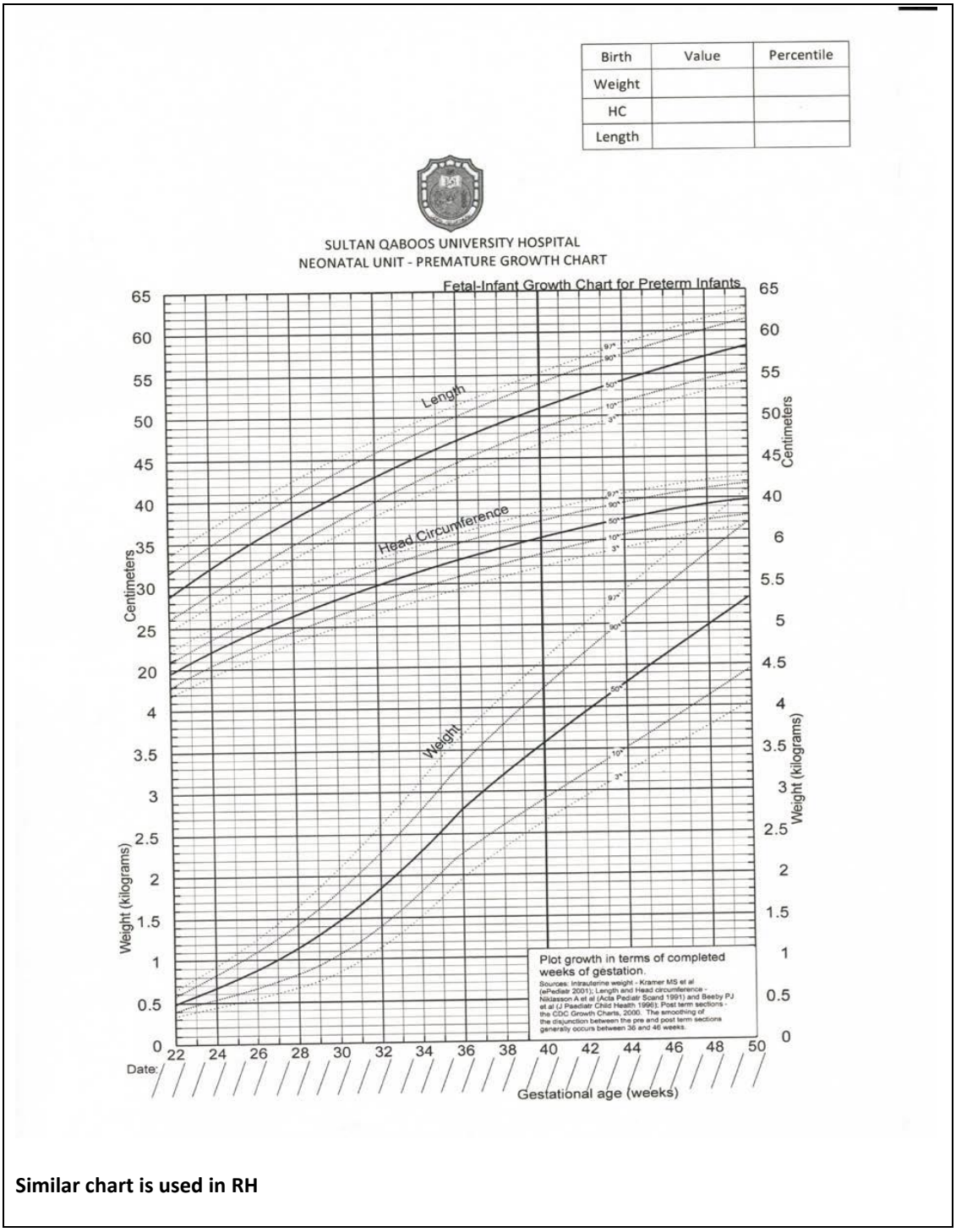
3.8.3 Indicator variables

Some indicator binary variables were created according to the information recorded in the participants' health records, including participants' PCOS status, diagnoses of GDM, PIH and preeclampsia, family histories of diabetes mellitus and hypertension and pregnancy outcome variables (miscarriage, stillbirth, ectopic, live).Moreover three variables, each identified by a criterion to diagnose PCOS as

per Rotterdam criteria, were created for each participant to indicate PCOS presence or absence. Among participants labelled with PCOS a new variable was created to indicate true cases and false cases requiring the presence or absence respectively of at least two out of the three criteria in diagnosing PCOS and the same was done among controls.

Similarly, information from medical records was used to indicate some neonates outcome variables including low APGAR score and NICU admission.

Other indicator variables for neonate outcomes were derived from other variables in the dataset such as the diagnosis of macrosomia which was true if the birth weight value was >=4kg and preterm delivery variable which was true if weeks of gestation value was <37 weeks. In addition a variable to indicate low weight for gestational age (LWGA) was created by charting each newborn's birth weight against a population standard chart for neonates (Figure 3.5), a weight below the 10th percentile for a specific gestational age was considered LWGA.



Similar chart is used in RH

Figure 3.5: Standardized chart for the diagnosis of low weight for gestational age infants

3.8.4 Data cleaning

The second stage was data cleaning, where data were checked for duplicates, implausible entries and wrongly calculated variables using various methods including plotting histograms, tabulating categorical variables, summarizing continuous variables and using conditional STATA commands to identify outliers. The database was further checked by the academic supervisors to ensure its readiness for analysis.

The third stage involved producing subsets of datasets from the cleaned dataset for analysis purposes (for metabolic, adverse birth and neonatal outcomes).These subsets of datasets will be further described in the chapters that follow.

3.9 Sensitivity analysis of exposure status classification

A sensitivity analysis was carried out among cases and controls to identify the accuracy of the labelled cases and selected controls based on physician's documentation of PCOS symptoms and signs. Records of the cases labelled with an ICD code for PCOS were further checked to ensure they met the Rotterdam criteria mentioned above. Among the 305 women with PCOS and with clinical information available on the features of their condition, only 5 (1.6%) did not meet the diagnosis criteria in such a way they had only one documented feature instead of at least two out of the three features to be diagnosed with PCOS according to Rotterdam criteria (and thus were labelled falsely as cases of PCOS). As expected, less clinical information on features of PCOS was available for the selected controls.

However, among the 119 controls in the dataset with available clinical information, only 2 (1.7%) were found to meet the PCOS criteria without being labelled and therefore were considered false controls. In contrast 98.4% and 98.3% of the included cases and controls in the study's database were true cases and true controls respectively leading to a sensitivity and specificity of 99.3% and 95.9% respectively table (3.8).

Table 3.8: Sensitivity and specificity of study's cases and controls classification

Participants			**Sensitivity and Specificity**	**Total**
Women with PCOS	**True cases** 300(98.4%)	**False cases** 5(1.6%)	Sensitivity = True positive/(true positive+ false negative) = 300/(300+2)*100=99.3%	305(100%)*
Women without PCOS	**True controls** 117(98.3%)	**False control** 2(1.7%)	Specificity = True negative/(true negative+ false positive) = 117/(117+5)*100=95.9%	119(100%)*

***Total participants with available clinical information on PCOS status**

3.10 Database statistics

The final created database included a total of 1,939 pregnancies (1,886 singleton and 53 multiple gestations). Overall, a total of 529 pregnancies were among 305 women with PCOS and a total of 1,410 pregnancies were among 617 women without PCOS. These pregnancies resulted in a total of 2000 foetuses. Among these foetuses, 1,716 were live-born neonates, 31 were ectopic pregnancies, 224 were miscarriages, 21 were stillbirths and 8 were multiple gestations resulted in a

combination of live and still born newborns. Further illustration of database population is shown in figure (3.6).

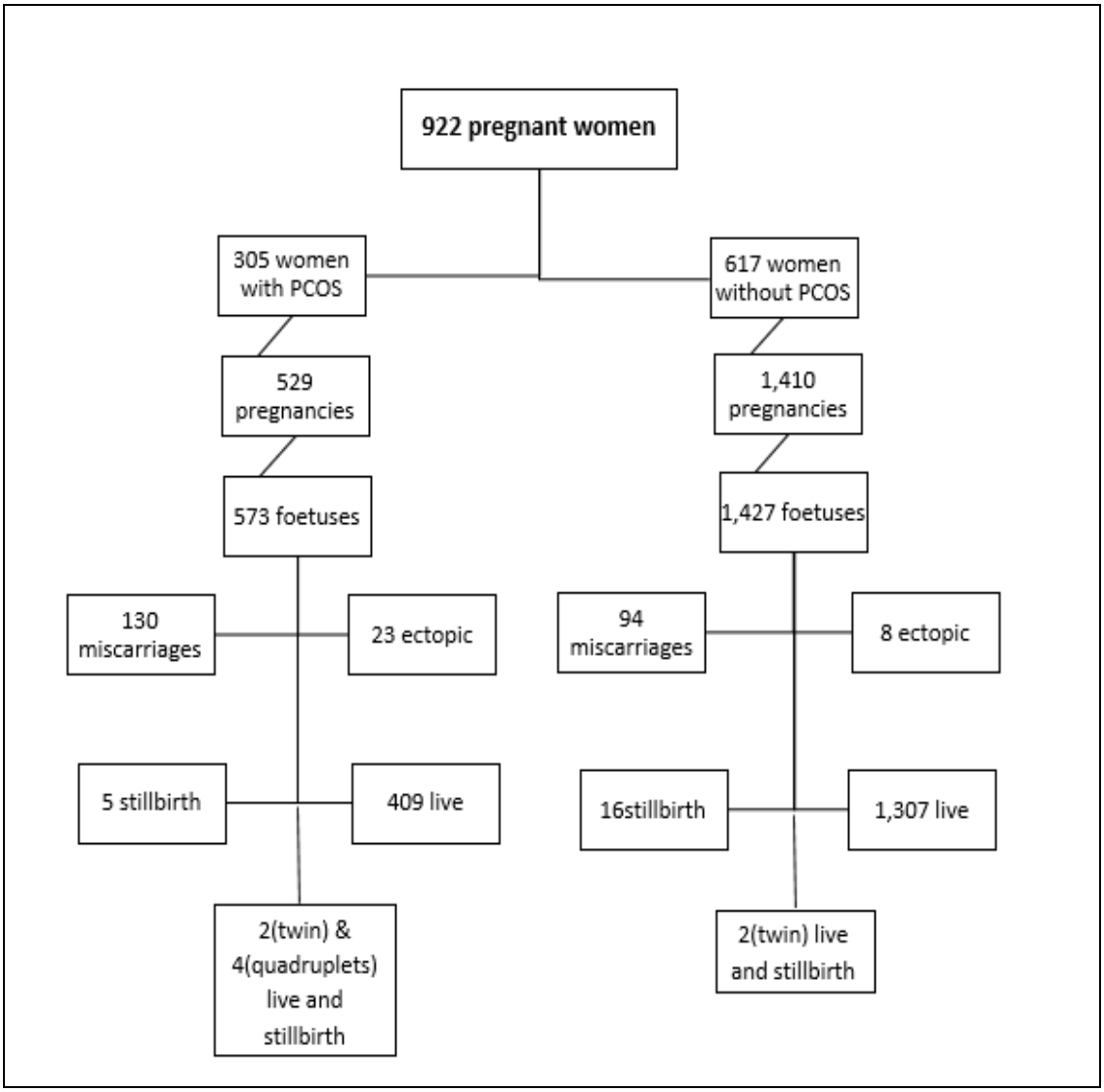


Figure 3.6: Flowchart of database population

3.11 Ethical approval

Patients treated in the two study hospitals (SQUH and RH) gave their data understanding that it might be used for research. Therefore data were accessed without patients' direct consent. However all personal identifiers have been removed and patients remained anonymized being only identified using their unique hospital record numbers. The dataset created for analysis was stored securely on a password-protected computer, with the files only visible to members of the research team. Ethical approvals have been awarded by the two study hospitals: Sultan Qaboos University Medical Ethics committee for SQU hospital (Appendix E1) and from Ministry of Health-Research and Ethical Review and Approve Committee-Directorate General for Planning and Studies for RH (Appendix E2). The researcher was also granted log in access to participants' health records in RH valid for 1 year and 6 months period. Access to SQUH medical records was available to the researcher for being a medical doctor and an employee of SQUH, however ethical approval was required in the latter to use patients' medical information for this research.

Ethical approval was also obtained from the ethical committee of the University of Nottingham's school of medicine (Appendix E3).

4 Effects of PCOS on pregnant women and their newborns

This chapter will first define the different study outcomes under analysis among mothers and their newborns to then describe the methodology used in the analysis of the created database (as discussed in chapter 3). Following, the results of each analysis will be presented and finally discussed in light with previous studies together with a discussion on strengths and limitations of the current study.

4.1 Introduction

4.1.1 Effects of PCOS on pregnant women and their newborns

Existing literature on the association between PCOS and various metabolic, pregnancy and newborn outcomes is controversial with conflicting results (as discussed in chapter1). This is mainly due to the discrepancies in the criteria followed to identify cases with PCOS, the small sample size included and the selection of a case control design which might have introduced selection and recall bias. Moreover majority of studies were conducted on population from Western countries (82, 83, 91, 102, 103, 107-109, 111, 138, 142, 319, 320) and very limited evidence exists on the Eastern population including those from the Middle East (98, 100, 101, 104, 112, 263, 321). This is the first study to examine the association between PCOS and metabolic, birth and neonatal outcomes among affected mothers in the Middle East including Omani pregnant women. The cohort study design included a relatively large number of women with PCOS (n=305) diagnosed according to Rotterdam criteria (322) and controlled for important confounders.

4.2 Methods

4.2.1 Data source

A study database was created using participants' medical health records from both study hospitals as discussed earlier in chapter 3. For maternal outcomes the unit of analysis was the pregnancy. A total of 1,939 pregnancies were obtained from 922 women with and without PCOS across the two study hospitals (SQUH & RH) as shown in figure (3.6) of chapter 3.

A subset from the main study's database was created for newborn-level outcomes. This included newborn outcomes of interest variables and the related variables of women and pregnancy characteristics needed for analysis. Newborn outcomes of interest were extracted from the same 922 participants' medical health records, as information on newborns medical condition post-delivery is normally recorded in a woman's delivery notes (Appendix B2-5). A total of 2000 foetuses from the 1,939 pregnancies were included in the study, of which 537 were from mothers with PCOS and 1,427 from mothers without PCOS. Among the total foetuses, 114 were from multiple gestations, 1,721 were live born, 224 were miscarriages, 31 were ectopic and 24 were stillbirths.

4.2.2 Study outcome measures

4.2.2.1 Metabolic outcomes among pregnant women with PCOS

The first objective of this study was to examine the following adverse maternal metabolic outcomes among pregnant women with PCOS: gestational diabetes mellitus (GDM), pregnancy induced hypertension (PIH) and preeclampsia.

1) Gestational diabetes mellitus

Gestational diabetes also known as Gestational Diabetes Mellitus (GDM) is defined as high glucose levels in the third trimester among pregnant women who have never had diabetes before pregnancy(87). Diagnosis is based on a 2-hour 75gm Oral Glucose Tolerance Test (OGTT) of >=8.5 mmol/L (>=153mg/dl) in the third trimester of gestation (>20 weeks of gestation). As gestational diabetes is more common among non-white ethnic groups, especially south and south-east Asians (30), a random non-fasting blood sugar screening is done for all Omani pregnant women at their first antenatal visit (<24 weeks of gestation). Women with a normal reading at booking will further undergo an oral glucose tolerance test (OGTT) at 24-28 weeks gestation to check for GDM. Those with an abnormal blood sugar test (non-fasting blood sugar or glycated haemoglobin test (HbA1c)) result at their first antenatal visit will undergo a fasting blood sugar (FBS) test. A diagnosis of either GDM or overt (chronic) diabetes mellitus will be made based on this reading. In such a way a FBS reading of >= 5.1 and <7 mmol/L would indicate a diagnosis of GDM while a FBS reading of >=7mmol/L means patient has an overt diabetes mellitus (DM)(29). Figure (4.7) is a flow chart of GDM diagnosis in Oman health institutions.

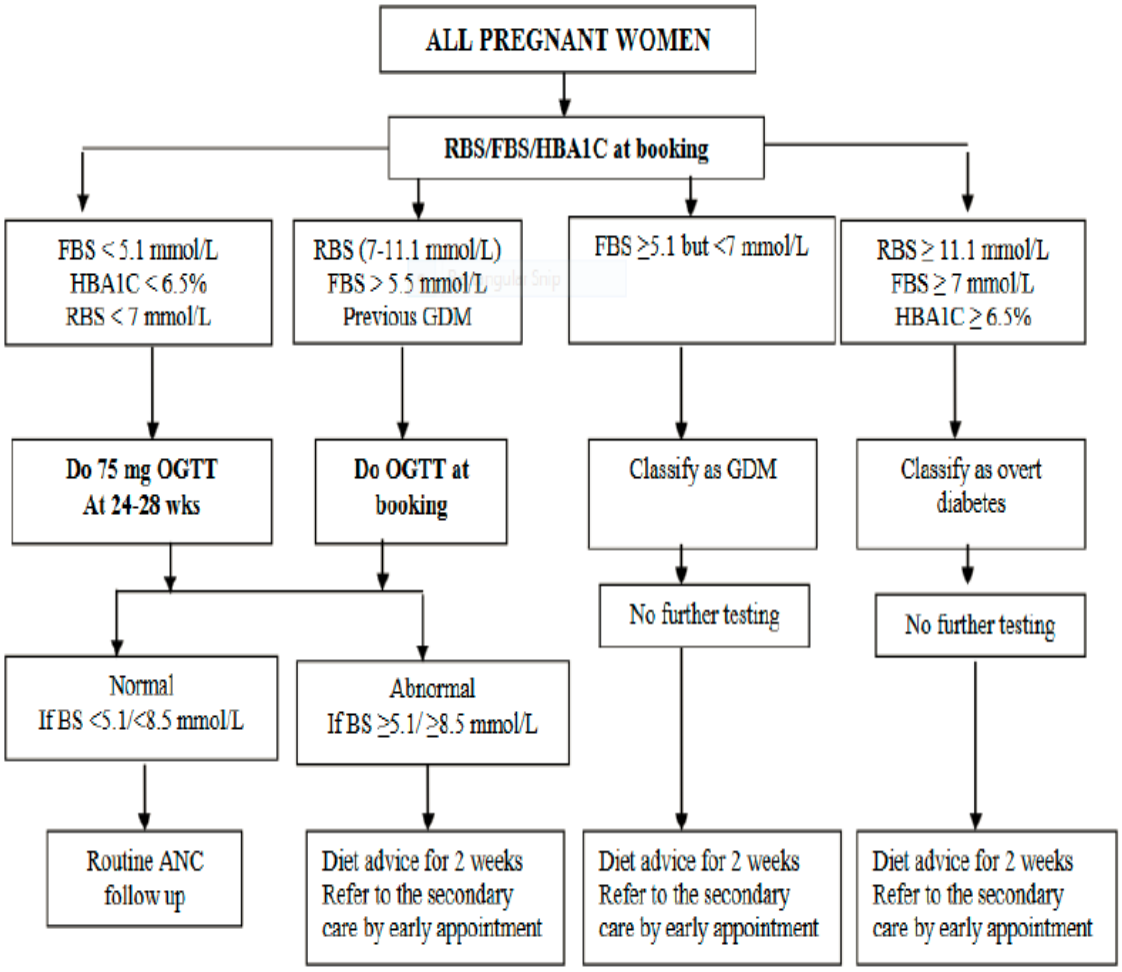


Figure 4.7: Flowchart of the diagnosis of gestational diabetes in Oman

2) Pregnancy induced hypertension

Pregnancy induced hypertension (PIH) refers to high blood pressure (>=140/90 mmHg) after the 20th week of gestation documented on two occasions at least 4 hours apart in women with normal blood pressure before pregnancy(323). Blood pressure is routinely checked during each visit for early detection of PIH. Women with high blood pressure before the 20th week of gestation are considered to have chronic hypertension(324).

3) Preeclampsia

Both PIH and chronic hypertension (hypertension before or early in pregnancy) among pregnant women can lead to a more severe condition called preeclampsia or toxaemia after the 20th week of gestation, characterised by high blood pressure (>=140/90mmHg) and high level of proteins (proteinuria) in the urine(324). Symptoms include, severe headache, changes in vision, upper abdominal pain, nausea and vomiting and shortness of breath. Blood test results might show impaired liver function and decreased levels of platelets (thrombocytopenia)(323).

4.2.2.2 Birth related outcomes among pregnant women with PCOS

The second objective of the study was to examine various adverse birth outcomes among pregnant women with PCOS and these are:

1. Miscarriage: loss of the embryo before the 21st week of gestation

2. Preterm delivery: delivery before 37 weeks of gestation .This is further classified into:

- Extremely preterm: >=24 to <28 weeks
- Very preterm: >=28 to <32 weeks
- Moderate to late preterm: >=32 to <37 weeks

3. Caesarean section (C-section): a surgical procedure in which incision is made through a woman's abdomen and uterus to deliver her baby. Patients in Oman have the choice to opt for elective C-section without a medical necessity (e.g. breech pregnancy, previous C-section, emergency). However C-section is considered an adverse birth outcome in this study; therefore, only cases with emergency or medically planned C-section were considered and not the elective ones.

4. Stillbirth: intrauterine foetal death after 24 weeks of gestation. This term in Oman is specifically used for foetal death that occurs at time of delivery where resuscitation is possible, whereas the term intrauterine foetal death (IUFD) is used if foetal death occurred after 24 weeks of gestation and dismissed where resuscitation is not possible.

4.2.2.3 Outcomes in newborns to mothers with PCOS

The third study objective is to examine the following outcomes among newborns to mothers with PCOS:

1. Macrosomia: birth weight of 4000g or more (this cut- point is used in Oman based on Omani population standards)

2. Low Weight for Gestational Age (LWGA): babies with birth weight below the 10th percentile for the gestational age according to the studied population's standards (see figure 3.3 in chapter 3)

3. Low APGAR score: APGAR is an evaluation of the newborn baby on five criteria (**A**ppearance**, P**ulse**, G**rimace**, A**ctivity**, R**espiration)**.** A scale is given from 0 to 2 on each measure at 1 and 5 minutes after birth. Low APGAR is defined as a score of <7 out of 10 at five minutes after delivery (89)

4. Neonatal Intensive Care Unit (NICU) admission: admission of newborns to an intensive care unit due to illness or prematurity

4.2.3 Study design

This was a retrospective cohort study where the exposed group was represented by Omani pregnant women with PCOS and the unexposed group by Omani pregnant women without PCOS.

4.2.4 Exposure variables

For mother related outcomes the unit of analysis was the pregnancy therefore the exposed group was pregnancies of women with PCOS. On the other hand the unexposed group for mother related outcomes was pregnancies to women without PCOS. While for newborn related outcomes the exposed group was foetuses conceived and born to mothers with PCOS and the unexposed group was foetuses conceived and born to mothers without PCOS. For inclusion and exclusion criteria of mothers see Table (3.5) in Chapter 3, p63.

4.2.5 Confounding variables

All women and pregnancy characteristics were included as confounders in the analysis for both maternal and birth outcomes, regardless of the significance level of their difference between the exposed and the unexposed groups, as they all were believed to have a possible confounding effect on the outcomes of interest. Confounder variables were participant's hospital of follow up, place of residence, level of education, employment status, mode of conception, number of foetuses in a gestation, number of previous miscarriages, number of previous stillbirths, number of previous ectopic pregnancies, number of previous IUFD, gravidity status, parity status and family histories of diabetes mellitus and hypertension. For further variable characteristics see variables dictionary (Appendix D).

4.2.5.1 Weight assessment

Participants' weight measurements in the health systems of the two hospitals were recorded at different gestational age during each pregnancy. Since pregnancies among women with PCOS are considered at high risk and many women succeeded to carry a pregnancy using ARTs in fertility clinics of the study hospitals, their weight recording tended to be measured earlier during their pregnancy and more frequently up to the delivery date. On the other hand, the majority of the controls with low risk pregnancies were referred to the tertiary hospitals only during their third trimester for follow up prior to delivery, therefore most weight measurements were recorded late during pregnancy. Moreover, for un-booked cases who walked in to the emergency department in labour without a prior visit to the clinic in their third trimester, the weight measurement was recorded only at delivery.

The researcher obtained all available weight measurements of study participants from the hospital systems but a preliminary analysis showed the majority of available participants' weight recordings was measured late during pregnancy. Maternal weight, to be considered as a risk factor on pregnancy or birth outcome, should be captured early during pregnancy (first trimester or just before conception) and since this information was missing for the majority of participants, weight could not be controlled for as a confounder in the analysis.

4.2.6 Statistical methods

4.2.6.1 Clustering levels

This study collected data on different pregnancies (different points in time) from the same group of women in two selected hospitals. This introduced different levels of clustering effect that had to be accounted for in the analyses.

4.2.6.1.1 Clustering in women related outcomes

For women related outcomes there were two levels of clustering; the first level was within women (multiple pregnancies among the same women) and the second level was within the study hospitals. These two factors might have introduced random effects on the studied correlation between the exposure (PCOS) and the outcomes of interest, therefore they were controlled for in the analysis through the use of multilevel models.

4.2.6.1.2 Clustering in newborn related outcomes

For newborn related outcomes there were three levels of clustering; the first level was within pregnancies (in multiple gestations), the second level was within women (multiple pregnancies among the same women) and the third level was within the study hospitals. Similarly these factors might have introduced random effects on the studied correlation between the exposure (PCOS) and the outcomes of interest among newborns, therefore they were controlled for in the analysis through the use of multilevel models.

4.2.6.2 Analysis of metabolic and pregnancy related outcomes

First, crude odds ratios of each outcome were calculated to assess the association between PCOS and the adverse metabolic and pregnancy outcomes, compared to the unexposed group, applying a multilevel logistic model to account for clustering. Second, the association between different confounders (listed under: confounding variables, p 84) and both the exposure (PCOS) and the outcome variables of interest were examined using multivariable multilevel logistic models to account for both clustering and confounders.

Logistic model was chosen given all outcomes of interest were binary variables. For both metabolic and pregnancy related outcomes there were two levels of clustering by hospital of study and women. Adjusted odds ratios of the outcomes were obtained along with 95% confidence intervals (95% CI). The statistical software program STATA SE 14.0 was used for analysis and a p value of <=0.05 was considered significant.

4.2.6.3 Analysis of newborn related outcomes

Similarly to women related outcomes, first, crude odds ratio of each newborn outcome was calculated comparing the exposed to unexposed group applying a multilevel logistic model to account for clustering. Second, the association between different confounders (listed under: confounding variables, p 84) and the exposure (PCOS) and outcome variables of interest among newborns were examined using multivariable multilevel logistic models to account for both clustering and confounders. Logistic model was chosen again given all newborn outcomes of interest were categorical variables. For newborn related outcomes there were

three levels of clustering by hospital of study, women and gestations per woman. Adjusted odds ratios of outcomes were obtained along with 95% CI. The statistical software program STATA SE 14.0 was used for analysis and a p value of <=0.05 was considered significant.

4.2.7 Missing data

The missing data on women related outcomes of interest were very minimal ranging from 0.0% - <1.0%. In addition missing data on newborn related outcomes were also very minimal ranging from 0.0% to 0.5%, therefore missing data were left unchanged and grouped as a separate category, as it was unlikely to affect the analysis

4.3 Results

4.3.1 Study population characteristics

Demographic characteristics of the 922 total parturient women of the study's cohort are listed in Table (4.9).Those characteristics remained constant for each woman throughout their pregnancies, as they were recorded only once during the patient's first visit ever to the hospital to create her medical profile. The two exposed groups showed no significant difference in their distribution across their hospital of follow up and place of residence ($p>0.05$). However more women with PCOS had University or higher level of education (37.1%) compared to women without PCOS (32.9%) ($p=0.020$). Moreover significantly higher number of women with PCOS were employed (45.6%) compared to women without PCOS (33.9%) ($p<0.001$).

Table 4.9:Distribution of the demographic characteristics of study's sample (n=922 women)

Participants' characteristics	All Participants (n=922) n(%)	Participants with PCOS (n=305) n(%)	Participants without PCOS (n=617) n(%)	*p* value
Study's hospital				
SQUH	263(28.5)	96(31.5)	167(27.1)	0.163*
RH	659(71.5)	209(68.5)	450(72.9)	
Residence				0.623*
Urban	639(69.3)	207(67.9)	432(70.0)	
Rural	279(30.3)	95(31.2)	184(29.8)	
missing	4(0.4)	3(0.9)	1(0.2)	
Educational level				0.020*
Primary/less	79(8.6)	26(8.5)	53(8.6)	
Secondary	351(38.1)	102(33.4)	249(40.4)	
University/higher	316(34.3)	113(37.1)	203(32.9)	
missing	176(19.1)	64(20.9)	112(18.2)	
Employment level				0.001*
Employed	348(37.7)	139(45.6)	209(33.9)	
Unemployed	558(60.5)	163(53.4)	395(64.0)	
missing	16(1.7)	3(0.9)	13(2.1)	

***Chi square test**

1.1.1 Weight assessment results

Table (4.10) summarizes participants' mean weight measurements at different gestational age of their pregnancies, stratified by their PCOS status.

Table 4.10: Mean weight distribution among pregnancies of women with and without PCOS at different weeks of gestation

Week of gestation	No. of pregnancies among women with PCOS(n=1,774)	% of pregnancies among women with PCOS	No. of pregnancies among women without PCOS(n=2,385)	% of pregnancies among women without PCOS	Mean weight for women with PCOS(Kg)	Mean weight for women without PCOS(Kg)
5	53	2.9%	11	0.5%	73.9	62.1
6	54	3.0%	15	0.6%	73.7	71.3
7	43	2.4%	21	0.9%	74.1	67.7
8	45	2.5%	19	0.8%	80.6	68.8
9	34	1.9%	11	0.5%	76.5	69.9
10	21	1.2%	21	0.9%	76.3	67.1
11	53	2.9%	23	1.0%	75.4	63.1
12	32	1.8%	19	0.8%	74.5	66.8
13	37	2.1%	23	1.0%	72.1	71.4
14	32	1.8%	22	0.9%	80.9	71.0
15	33	1.9%	22	0.9%	74.0	65.8
16	34	1.9%	24	1.0%	74.1	71.8
17	42	2.4%	29	1.2%	75.6	71.3
18	26	1.5%	21	0.9%	79.3	67.0
19	48	2.7%	24	1.0%	80.1	69.2
20	35	2.0%	33	1.4%	77.6	73.1
21	33	1.9%	32	1.3%	76.6	71.4
22	41	2.3%	40	1.7%	79.5	69.4
23	42	2.4%	49	2.1%	82.8	72.5
24	39	2.2%	36	1.5%	76.4	75.3
25	36	2.0%	41	1.7%	79.7	74.8
26	43	2.4%	45	1.9%	80.9	72.1
27	38	2.1%	63	2.6%	77.7	73.8
28	46	2.6%	71	3.0%	78.8	74.5
29	51	2.9%	73	3.1%	84.1	76.4
30	41	2.3%	77	3.2%	78.9	76.5
31	59	3.3%	81	3.4%	81.9	73.9
32	57	3.2%	104	4.3%	84.2	77.0
33	67	3.8%	104	4.3%	86.8	75.7
34	78	4.4%	124	5.2%	87.3	77.4
35	88	4.9%	149	6.2%	84.9	76.7
36	97	5.5%	182	7.6%	81.4	76.6
37	107	6.0%	62	2.6%	84.7	75.2
38	46	2.6%	204	8.6%	86.7	75.9
39	35	2.0%	200	8.4%	80.6	75.5
40	18	1.0%	104	4.3%	86.4	74.2
41	0	0%	26	1.1%	-	-

42	0	0%	2	0.1%	-	-

Figure (4.8) shows a line chart comparing the mean weight measurements in kilograms between women with PCOS and without PCOS at different gestational age. Women with PCOS were found to have higher weight measurements compared to women without PCOS in the first, second and third trimesters.

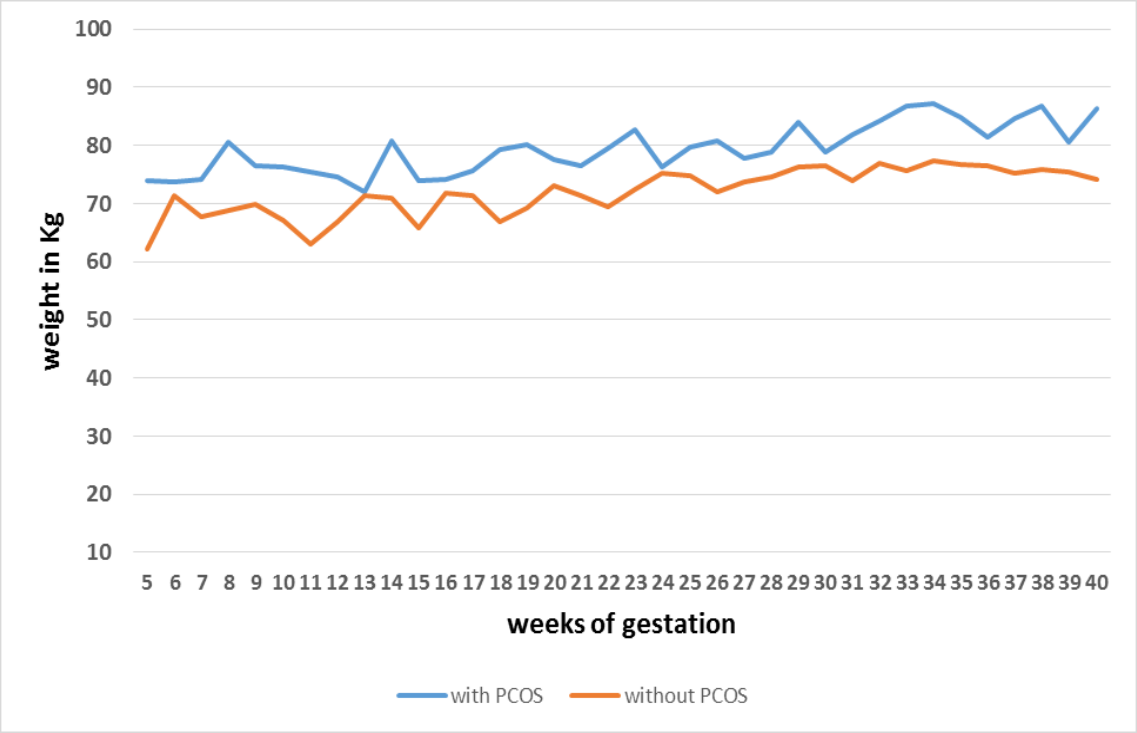


Figure 4.8: Line chart comparing mean weight measurements of women with and without PCOS during pregnancy at different gestational age

Table (4.11) summarizes body mass index (BMI) for weight recorded early during pregnancy (5-16 weeks of gestation) among pregnancies of women with and without PCOS. Among the available 4,028 weight recordings at different gestational age of participants' pregnancies, only 681 (16.9%) weight recordings were available

at the early weeks of gestation (5-16 weeks) of participants' pregnancies (if weight was recorded more than once for a participant's pregnancy at the same gestational week the mean was computed).

Majority of women with PCOS (37.8%) and without PCOS (38.6) were overweight in their first trimester, however higher proportion of women with PCOS were obese and morbidly obese compared to women without PCOS at this same time period,(31.1% vs 26.8% and 25.2% vs 13.6% respectively, p <0.001) .

Table 4.11: BMI categories of women with and without PCOS in the first trimester

BMI category	Pregnancies among women with PCOS(n=453) n(%)	Pregnancies among women without PCOS(n=228) n(%)	Fisher's exact test p -value
Underweight (<18.9)	3(0.7)	8(3.5)	<0.001
Normal(19-24.9)	34(5.3)	39(17.1)	
Overweight(25-29.9)	171(37.8)	88(38.6)	
Obese(30-34.9)	141(31.1)	61(26.8)	
Morbidly obese(>35)	114(25.2)	31(13.6)	
Missing*	0(0.0)	1(0.4)	

***the height value is missing**

4.3.2 Effects of PCOS on pregnant women

4.3.2.1 Pregnancy characteristics among the two study groups

There was a total of 1,939 pregnancies among the 922 women in the study. The pregnancies' characteristics and outcomes are summarized in Table (4.12). A significantly higher proportion of women without PCOS had pregnancies at a younger age (15-25 years) and at a higher age (40-50 years) in comparison to women with PCOS (23% vs 15.2% and 3.4% vs 1.3% respectively, p<0.001).

Furthermore women without PCOS had higher gravidity and parity status of 4 and more when compared to those with the disease 33.0% vs 22.5% and 13.7% vs 4.2% respectively ($p<0.001$). In general, more women without PCOS conceived naturally compared to women with PCOS (99.1% vs 61.6%, $p <0.001$) whereas a significantly higher proportion of those with PCOS conceived using different assisted reproductive techniques (37.9% vs 0.9%, $p<0.001$). A significantly higher proportion of women with PCOS had history of previous ectopic (4.2% vs 1.2%), miscarriage (36.9% vs 22. 1%) and stillbirth (2.1% vs 0.5%) as pregnancy outcomes ($p<0.05$) but no significant difference between the two groups was found in history of previous IUFD ($p=0.20$).

When family histories of DM and HTN were examined among the current 1,692 pregnancies in the study that lasted at least until 20 weeks of gestation(for these outcomes to be diagnosed) no significant difference was detected between the two groups ($p=0.14$ and 0.18 respectively).

Among the current 1,939 pregnancies included in this study, live births were more common for women without PCOS compared to women with PCOS (91.6% vs 71.3, $p<0.001$). On the other hand significantly more miscarriages (23.4% vs 6.7%) and ectopic pregnancies (4.2% vs 0.6%) were observed among women with PCOS ($p<0.001$) compared to the controls.

Table 4.12: Distribution of previous and current pregnancy characteristics of 1,939 pregnancies among women with and without PCOS

Participants pregnancies characteristics	**All Pregnancies(n=1,939)** **n(%)**	**Pregnancies among women with PCOS (n=529)** **n(%)**	**Pregnancies among women without PCOS (n=1,410) n(%)**	***p* value**
Age category(year)				<0.001*
15-20	43(2.2)	3(0.6)	40(2.8)	
20-25	347(17.9)	77(14.6)	270(19.2)	
25-30	741(38.2)	212(40.1)	529(37.5)	
30-35	515(26.6)	164(31.0)	351(24.9)	
35-40	238(12.3)	66(12.5)	172(12.2)	
40-50	55(2.8)	7(1.3)	48(3.4)	
Mode of conception				<0.001**
Natural	1,725(88.9)	326(61.6)	1,399(99.1)	
Metformin	5(0.3)	5(0.9)	0(0.0)	
Clomid	108(5.6)	100(18.9)	8(0.6)	
IUI	35(1.8)	33(6.2)	2(0.1)	
IVF	66(0.1)	63(11.9)	3(0.2)	
Number of foetuses in current pregnancy				<0.001**
1	1,886(97.3)	493(93.2)	1,393(98.8)	
2	46(2.4)	29(5.5)	17(1.2)	
>=3	7(0.4)	7(1.32)	0(0.0)	
Pregnancy outcome				<0.001**
Live	1,669(86.1)	377(71.3)	1,292(91.6)	
Miscarriage	218(11.2)	124(23.4)	94(6.7)	
Ectopic	30(1.6)	22(4.2)	8(0.6)	
Stillbirth	19(0.9)	4(0.8)	15(1.1)	
Live and stillbirth	3(0.2)	2(0.4)	1(0.1)	
				<0.001**

Previous ectopic 0 1 >=2	1,900(97.9) 35(1.8) 4(0.2)	507(95.8) 19(3.6) 3(0.6)	1,393(98.8) 16(1.1) 1(0.1)	
Previous miscarriage*** 0 1 2 3 >=4	 1,430(73.8) 314(16.2) 128(6.6) 35(1.8) 32(1.7)	 334(63.1) 105(19.9) 46(8.7) 21(3.9) 23(4.4)	 1,096(73.7) 209(14.8) 82(5.8) 14(0.9) 9(0.6)	<0.001*
Previous IUFD+ 0 1 >=2	 1,910(98.5) 23(1.2) 6(0.3)	 525(99.2) 4(0.8) 0(0.0)	 1,385(98.2) 19(1.4) 6(0.4)	0.200**
Previous stillbirth++ 0 1 >=2	 1,923(99.1) 15(0.8) 3(0.2)	 518(97.9) 10(1.9) 1(0.2)	 1,403(99.5) 5(0.4) 2(0.1)	0.002**
Gravida status 1 2 3 >=4	 536(27.6) 500(25.8) 320(16.5) 583(30.1)	 193(36.5) 141(26.7) 76(14.4) 119(22.5)	 343(24.3) 359(25.4) 244(17.3) 464(33.0)	<0.001*
Para status 0 1 2 3 >=4	 707(36.5) 511(26.3) 312(16.1) 194(10.0) 215(11.1)	 313(59.2) 121(22.9) 50(9.5) 23(4.4) 22(4.2)	 394(27.9) 390(27.7) 262(18.6) 171(12.1) 193(13.7)	<0.001*
Pregnancy characteristics among 1,692 pregnancies lasted at least up to 20 weeks of gestation				
Pregnancy characteristic	**All pregnancies (n-=1,692)** **n(%)**	**Pregnancies among women with PCOS (n=383)** **n(%)**	**Pregnancies among women with PCOS (n=1,309) n(%)**	**Statistical test- p value**
Family history of diabetes mellitus Yes No	 232(13.7) 111(6.6) 1,349(79.7)	 112(29.2) 63(16.5) 208(54.3)	 120(9.2) 48(3.7) 1,140(87.2)	0.140*

missing				
Family history of hypertension Yes No missing	195(11.5) 142(8.4) 1,354(80.1)	94(24.5) 79(20.6) 210(54.8)	101(7.7) 63(4.8) 1,144(87.5)	0.180*

***Chi square test**
****Fisher's exact test**
*****Miscarriage: loss of the embryo before the 21st week of gestation**
+IUFD: intrauterine foetal demise after 21 weeks of gestation, where resuscitation is not possible
++Stillbirth: newborn's fresh death after 21 weeks of gestation but during or right after delivery, where resuscitation is possible

4.3.2.2 Metabolic and adverse birth outcomes

Table (4.13) presents the distribution of various metabolic outcomes among the exposed and the non-exposed groups. These outcomes were examined among 1,692 pregnancies that reached at least the 20th week of gestation for the diagnoses of GDM, PIH and preeclampsia to be made. The diagnosis of GDM was found to be significantly higher among women with PCOS (34.9% vs 16.7%, $p<0.001$) and there was a significantly higher proportion of women diagnosed with PIH compared to those without PCOS (13.3% vs 5.6%, $p<0.001$). However no significant difference was observed between the two groups for the diagnosis of preeclampsia ($p=0.08$).

When the adverse birth outcomes of preterm delivery and mode of delivery were examined among this group of pregnancies, significantly higher proportion of women with PCOS delivered preterm (before 37 weeks of gestation) compared to women without PCOS (19.1% vs 6.8%, $p<0.001$). In addition a significantly higher proportion of women with PCOS delivered by emergency C-section compared to women without PCOS (30.8% vs 12.9%, $p<0.001$).

Table 4.13: Distribution of metabolic and adverse pregnancy outcomes among 1,691 pregnancies lasted >=20 weeks of gestation (a subset from all pregnancies n=1,939, excluding miscarriages (n=219) and ectopic pregnancies (n=30))

Participants pregnancies characteristics	**All Pregnancies (n=1,691)** **n(%)**	**Pregnancies among women with PCOS (n=383)** **n(%)**	**Pregnancies among women without PCOS (n=1,308)** **n(%)**	***p* value**
Gestational diabetes(GDM)				<0.001*
Yes	352(20.8)	134(34.9)	218(16.7)	
No	1,332(78.8)	246(64.2)	1,086(83.0)	
missing	7(0.4)	3(0.8)	4(0.3)	
Pregnancy induced hypertension(PIH)				<0.001*
Yes	124(7.3)	51(13.3)	73(5.6)	
No	1,563(92.4)	331(86.4)	1,232(94.2)	
missing	4(0.2)	1(0.3)	3(0.2)	
Preeclampsia				0.08*
Yes	34(2.0)	12(3.1)	22(1.7)	
No	1,653(97.8)	370(96.6)	1,283(98.1)	
missing	4(0.2)	1(0.3)	3(0.2)	
Term delivery at 37 weeks of gestation				<0.001*
Yes	1,524(90.1)	311(81.2)	1,213(92.7)	
No	164(9.7)	71(18.5)	93(7.1)	
missing	3(0.2)	1(0.3)	2(0.2)	
Mode of delivery				<0.001*
Spontaneous	1,231(72.8)	223(58.2)	1,008(77.1)	
Assisted	58(3.4)	10(2.6)	48(3.7)	
Elective C-section	110(6.5)	30(7.8)	80(6.1)	
Emergency C-section	287(16.9)	118(30.8)	169(12.9)	
missing	5(0.3)	2(0.5)	3(0.2)	

***chi square test**

Table (4.14) presents the unadjusted and adjusted multilevel logistic regression models results for the metabolic outcomes GDM, PIH and preeclampsia and for the adverse pregnancy outcomes namely preterm delivery and delivery by emergency C-section. Two random factors were included in these models to control for clustering at the level of hospital of study and women.

In the unadjusted model the odds of GDM was found to be 4.01 times higher among women with PCOS compared to women without (95% CI 2.56 - 6.30, p<0.001) while for PIH it was 3.74 times higher among the exposed group and this was a statistically significant difference (95% CI 1.84 -7.63, p<0.001). However the risk of preeclampsia was not significantly different between the two groups (p=0.248).

For adverse birth related outcomes, the unadjusted model showed women with PCOS were 4.27 times more likely to go through preterm delivery compared to women without PCOS (95% CI 2.65-6.90, p<0.001). Similarly the odds of undergoing emergency C-section was 6.51 times higher among pregnant women with PCOS when compared to those without PCOS (95%CI 3.59 – 11.81, p<0.001).

Adjusted model was created in STATA for the outcomes of interest. The model included almost all women characteristics including age, educational level, employment status, residence area, number of previous miscarriages, previous stillbirths and previous ectopic pregnancies, number of foetuses in the current gestation, conception method, gravidity and parity status. This model was also accounted for clustering.

A second adjusted model was also assessed including two more variables namely participants' family histories of DM and HTN in addition to all the previous variables adjusted for in the first model. However, this second model had low observation counts due to the considerably high proportion of missing data in these two variables (79.7% and 80.1% respectively) compared to the variables included in the first adjusted model. Therefore obtained results were not considered reliable thus not shown.

In the adjusted model women with PCOS were found to be 2.38 times more likely to develop GDM (95% CI 1.38-4.10, p 0.002) and 2.65 times more likely to develop PIH (95% CI 1.11-6.31, p 0.028) compared to women without PCOS. However the risk of preeclampsia remained statistically not significant among the two groups (p 0.161). When adverse birth related outcomes were examined, women with PCOS were found to be 3.13 times at increased risk of having preterm delivery (95% CI 1.61-6.10,p 0.001) and 3.64 times more likely to undergo emergency C-section (1.61-8.23,p 0.002).

Table 4.14: Unadjusted and adjusted multilevel regression models for metabolic and adverse birth related outcomes among 1,691 pregnancies lasted >=20 weeks of gestation

		Unadjusted+	Adjusted +*	
Pregnancy outcomes	**Pregnancies among women with PCOS (n=383) n (%)**	**Pregnancies among women without PCOS (n=1,308) n (%)**	**Odds Ratio (95% CI)**	**Odds Ratio (95% CI)**
Gestational diabetes (GDM)	134(34.9)	218(16.7)	4.01 (2.56 - 6.30)	2.38 (1.38-4.10)
Pregnancy induced hypertension (PIH)	51(13.3)	73(5.6)	3.74 (1.84 - 7.63)	2.65 (1.11-6.31)
Preeclampsia	12(3.1)	22(1.7)	1.98(0.70 - 5.61)	2.86 (0.66-12.46)
Preterm delivery (23>=&<37 weeks of gestation)	73(19.1)	89(6.8)	4.27 (2.65 - 6.90)	3.13 (1.61-6.10)
Mode of delivery Emergency C-section	118(30.8)	169(12.9)	6.51 (3.59-11.81)	3.64 (1.61-8.23)

only pregnancies at >=20 weeks of gestation included
+random factors controlled for in the model: study hospital and woman
***adjusted for participant's age, education level, employment status, residence area, mode of conception, No. of foetuses, No. of previous miscarriages, No. of previous still births, No. of previous ectopic, No. of previous IUFD, gravidity status and parity status**

4.3.2.3 Adverse pregnancy related outcomes

Table (4.15) presents unadjusted and adjusted results for adverse pregnancy outcomes namely miscarriage and stillbirth among all pregnancies in the dataset (n=1,939). In the unadjusted model women with PCOS were 4.99 (95% CI 3.48-7.17, p <0.001) times at higher risk to have miscarriage compared to women without PCOS. However no significant difference in risk of stillbirth was found among the two groups of women (OR 1.00, 95% CI 0.38-2.70, p 0.99).

In the adjusted model the odds of miscarriage among women with PCOS was 3.41(95% CI 2.23–5.22, p<0.001) times higher compared to women without PCOS. However the odds of stillbirth remained statistically non-significant (OR 1.07, 0.28-4.17).

Table 4.15: Unadjusted and adjusted multilevel regression models for adverse pregnancy outcomes among 1,939 pregnancies

			Unadjusted+	Adjusted+ *
Pregnancy outcomes	**Pregnancies among women with PCOS (n=529)** **n (%)**	**Pregnancies among women without PCOS (n=1,410)** **n (%)**	**Odds Ratio (95% CI)**	**Odds Ratio (95% CI)**
Miscarriage	124 (23.44)	94 (6.67)	4.99 (3.48-7.17)	3.41 (2.23-5.22)
Stillbirth	6 (1.13)	16 (1.13)	1.00 (0.38-2.70)	1.07 (0.28-4.17)

+random factors controlled for in the models: study hospital and women
***adjusted for participant's age, education level, employment status, residence area, mode of conception, No. of foetuses, No. of previous miscarriages, No. of previous still births, No. of previous ectopic, No. of previous IUFD, gravidity status and parity status**

4.3.3 Effects on newborns to mothers with PCOS

4.3.3.1 Newborn characteristics among the two study groups

Table (4.16) shows the different newborn characteristics among the exposed and the unexposed groups. Among all newborns in the dataset (n=2000) significantly higher proportion of live children were born to mothers without PCOS compared to mothers with PCOS (91.7% vs 72.1%, p<0.001).

Among the live newborns (n=1,721), more children from women with PCOS were born prematurely (before 37 weeks of gestation) and this was a statistically a significant difference (22.5% vs 6.6%, p<0.001). Although the observed median birth weight was found to be 0.2kg lower among newborns in the exposed group compared to those in the unexposed group (p<0.001), no significant difference was found among the two groups for the other birth weight related outcomes namely macrosomia and LWGA (p=0.45 and 0.28 respectively). Significantly higher proportion of newborns in the exposed group had low APGAR score (1.9% vs 0.6%, p<0.001) and subsequently significantly higher proportion of them was admitted to NICU when compared to controls (17.2% vs 5.4%, p<0.001).

Table 4.16: Distribution of newborns characteristics among all newborrn (n=2000) and live newborns (n=1,721)

Newborns outcomes	**All newborns (n=2000)** **(n%)**	**Newborns to mothers with PCOS (n=573)** **(n%)**	**Newborns to mothers without PCOS(n=1,427)** **(n%)**	***p* value**
Viability outcome Live Non live	1,721(86.1) 279(13.9)	413(72.1) 160(27.9)	1,308(91.7) 119(8.3)	<0.001*
Newborns outcomes	**All live newborns (n=1,721)** **n(%)**	**Live newborns to mothers with PCOS (n=413)** **n(%)**	**Live newborns to mothers without PCOS (1,308)** **n(%)**	
Gestational age at birth Preterm a. Extremely preterm (>=24 to <28 weeks)	11(0.6)	10(2.4)	1(0.1)	<0.001**
b. Very preterm(>=28 to <32 weeks)	23(1.3)	16(3.9)	(0.5)	
c. Late preterm (>=32 to <37 weeks)	146(8.5)	67(16.2)	79(6.0)	
Term (>=37 to <=42weeks)	1,529(88.8)	319(77.2)	1,210(92.5)	
Post term(>42weeks)	12(0.7)	1(0.2)	11(0.8)	

Weeks of gestation median(IQR)	39(2)	38(2)	39(2)	<0.001***
Birth weight (kg) median(IQR)	3.0(0.6)	2.9(0.7)	3.1(0.5)	<0.001***
Diagnosis of macrosomia				0.45*
Yes	42(2.4)	8(1.9)	34(2.6)	
No	1,675(97.3)	404(97.8)	1,271(97.2)	
missing	4(0.2)	1(0.2)	3(0.2)	
Diagnosis of LWGA				0.28*
Yes	240(13.9)	64(15.5)	176(13.5)	
No	1,477(85.8)	347(84.0)	1,130(86.4)	
missing	0(0.0)	0(0.0)	0(0.0)	
Low APGAR score				0.002**
Yes	12(0.7)	8(1.9)	4(0.3)	
No	1,706(99.1)	404(97.8)	1,302(99.5)	
missing	3(0.2)	1(0.2)	2(0.2)	
NICU admission				<0.001*
Yes	141(8.2)	71(17.2)	70(5.4)	
No	1,576(91.6)	340(82.3)	1,236(94.6)	
missing	4(0.2)	2(0.5)	2(0.2)	

***chi square test**
**** Fishers exact test**
***** Mann- whitney test**

4.3.3.2 Newborn outcomes

Table (4.17) presents the unadjusted and adjusted odds ratios for different outcomes namely macrosomia, LWGA, low APGAR score and NICU admission among of a total of 1,721 live newborns. There were 3 levels of clustering in the models represented by the hospital of study, woman, and pregnancies per woman. Newborns to mothers with PCOS were 20% more likely to be diagnosed with macrosomia compared to those born to mothers without PCOS, however this difference was not found to be statistically significant(OR 1.20,P=0.916). Moreover babies in the exposed group were found to be 25% less likely to have a diagnosis of

LWGA compared to babies in the non-exposed group however this was also not a significant difference either (p=0.316). On the other hand babies born to mothers with PCOS were 2.6 times more likely to be admitted in NICU (p<0.001), however they were 88% less likely to have low APGAR score compared to newborns to mothers without PCOS(p 0.021).

In the multilevel multivariable regression model, adjusted for all women and foetal characteristics except for mothers' family histories of DM and HTN, no significant difference was found in newborns weight outcomes of macrosomia and LWGA (p 0.868 and p 0.788 respectively). In addition newborns to mothers with PCOS were 47% and 52% less likely to have low APGAR score and to be admitted in NICU respectively compared to those born to mothers without the disease, however these differences were statistically non-significant (p 0.518 and p 0.557 respectively).

Table 4.17: Unadjusted and adjusted multilevel regression models for a total of 1,721 live newborns outcomes

			Unadjusted&	Adjusted& *
Live newborn outcomes	**Live newborns to women with PCOS (n= 413)** n(%)	**Live newborns to women without PCOS (n= 1,308)** n(%)	**Odds Ratio (95% CI)**	**Odds Ratio (95% CI)**
Macrosomia	8 (1.9)	34 (2.6)	1.20 (0.04 – 33.53)	0.78 (0.04-14.70)
LWGA	64 (15.5)	176 (13.5)	0.75 (0.43-1.31)	0.88 (0.34-2.28)
Low APGAR score	8 (1.9)	4(0.3)	0.12 (0.02-0.73)	0.53 (0.08-3.63)
NICU admission	71 (17.2)	70 (5.4)	2.16 (1.33-3.51)	0.48 (0.43-5.47)

&random factors controlled for in the models: study hospital, woman and pregnancy
***adjusted for participant's age, education level, employment status, residence area, mode of conception, No. of foetuses, No. of previous miscarriages, No. of previous still births, No. of previous ectopic, No. of previous IUFD, gravidity status and parity status**

4.4 Post-hoc power analysis

As discussed previously (chapter 3,section: power calculation, p 64), it was not possible to account for the impacts of clustering within hospitals, women and pregnancies when carrying out the initial power calculation as the relevant intraclass correlations were not known. In addition, the ratio between the PCOS and comparator groups in the final study was 2:1 rather than 1:1 as fewer than 500 women with PCOS had pregnancies at the two hospitals during the study period.

Table (4.18) shows the observed intraclass correlations at each level, obtained by post estimation from the crude multilevel models. Correlation is trivial at hospital level, and near unity within pregnancies. Design effects can therefore be estimated using the intracluster correlation for pregnancies within women.

Table 4.18: Observed intraclass correlations from multilevel models

Outcome	Within hospital		Within women		Within pregnancy	
	ICC	Mean cluster size	ICC	Mean cluster size	ICC	Mean cluster size
GDM	0.02	968	0.50	2	N/A	N/A
PIH	0.00	968	0.62	2	N/A	N/A
Preeclampsia	0.00	968	0.62	2	N/A	N/A
Miscarriage	0.00	968	0.21	2	N/A	N/A
Caesarean section	0.00	968	0.63	2	N/A	N/A
Preterm delivery	0.00	968	0.37	2	N/A	N/A
Stillbirth	0.00	968	0.27	2	N/A	N/A
NICU admission	0.00	858	0.50	2	~1.00	1.0
Macrosomia	0.00	858	0.49	2	~1.00	1.0
LWGA	0.00	858	0.39	2	0.61	1.0
Low APGAR score	0.00	858	0.15	2	0.64	1.0

ICC: Intraclass correlation

Table (4.19) shows the minimum detectable OR at 80% power and 5% significance accounting for the observed intraclass correlation, estimated for a 2:1 comparator: PCOS population structure and using the observed prevalence of each outcome among the comparator group. The effective sample size is, in each case, greater than the target of 1000 used as the basis for the original power calculation, so the available power was greater than the 80% target for the expected differences (chapter 3, table 3.6, p 64). For outcomes where the observed OR is below the critical ratio (stillbirth, macrosomia, LWGS and low APGAR score), there is a greater than 20% chance that a study of this size would miss a significant effect of that size if it was truly present in the source population.

Table 4.19: Critical odds ratios at 80% power and 5% significance given observed intraclass correlation and outcome probability among non-PCOS pregnancies

Outcome	Design effect	Effective sample size	Critical Odds Ratio (5% significance, 80% power)
GDM	1.50	1293	1.52
PIH	1.62	1197	1.93
Preeclampsia	1.62	1197	2.59
Miscarriage	1.21	1594	1.71
Caesarean section	1.63	1190	1.61
Preterm delivery	1.37	1415	1.66
Stillbirth	1.27	1527	2.60
NICU admission	1.50	1293	1.90
Macrosomia	1.49	1301	2.17
LWGA	1.39	1395	1.48
Low APGAR score	1.15	1686	1.43

4.5 Discussion

4.5.1 Main study findings

The study results showed Omani pregnant women with PCOS are more likely to develop GDM and PIH during pregnancy compared to women without PCOS. However no difference was found in the risk of developing preeclampsia between women with PCOS and women without PCOS in this study's cohort.

Findings also suggest Omani pregnant women with PCOS are more likely to have a miscarriage of their pregnancy and deliver prematurely before 37 weeks of gestation when compared to women without PCOS. In addition women with PCOS are more likely to undergo emergency C-section as a mode of delivery compared to women without PCOS.

This study also showed newborns to mothers with PCOS are not at an increased risk of adverse birth outcomes to those born to mothers without PCOS. In such a way there was no evidence of newborns to mothers with PCOS to have higher risk of macrosomia, LWGA, low APGAR score after birth or being admitted in NICU, compared to newborns to mothers without PCOS.

4.5.2 Comparison with other studies

Metabolic outcomes

This study found an association between PCOS and the development of both GDM and PIH among pregnant women. Results showed the odds of pregnant women with PCOS to have GDM and PIH were 2.38 (95% CI 1.38-4.10, p=0.002) and 2.65(95 % CI 1.11-6.31, p=0.028) times higher compared to women without PCOS. However the analysis showed no significant association between PCOS and preeclampsia in this study's cohort (OR 2.86, 95% CI 0.66-12.46, p=0.161). Findings of this study on GDM and PIH among Omani pregnant women with PCOS are in line with many other studies conducted worldwide assessing these outcomes (82, 101, 104, 105, 107, 108, 112, 321).

First, similar results were found in comparing our results to the few studies conducted in the neighbouring countries (in Asian continent) that have focused mainly on the risk of GDM among pregnant women with PCOS. A large cohort study involving 7,629 women with PCOS using the Taiwan national health insurance research database also found them to have a higher risk in developing GDM compared to controls(OR 2.15; 95% CI 1.96–2.37) (104). Another case control study by Wijeyaratre et al. (2006) showed an association of PCOS with GDM among 274 Sri Lankan women compared to 168 ethnically matched controls attending a tertiary university hospital in Colombo, Sri Lanka(105). Similar to our study these studies, although included a large sample size, failed to control for participant's BMI. However, some of the studies that have controlled for BMI have also found a positive association between PCOS and GDM(321). A study by Weerakiet et al.

(2004) on Asian women compared 47 pregnancies in 41 women with PCOS to 264 pregnancies in 222 control women and found PCOS to be an independent risk factor for GDM after controlling for participant's BMI (112). Similarly to another case-control (2008) study on 94 Iranian women with GDM who had a significant history of PCOS when this latter was compared to controls and adjusting for their BMIs(101). However the small number of women in the former study and the study design in the latter might have affected the findings.

On the other hand a couple of studies from other developing countries showed negative association between PCOS and GDM: the first (2003) was among 38 Turkish women with PCOS compared to 136 controls(100) and the second (2009) was among 56 Indian women with PCOS and controls matched for age and weight (98). However, the small sample size included in these studies might have made it hard to detect any association if it had existed.

A bulk of studies on metabolic outcomes among women with PCOS were carried out on populations from Western countries. Many of the available published meta-analyses studies by Boomsma et al.(2006) (including 15 studies)(107), Kjerulff et al. (2011)(including additional 8 studies)(108) and Qin et al. (2013) (including additional 4 studies)(82) supported the association between PCOS and GDM, PIH and preeclampsia. However the included studies were mostly case control in design, included small counts (<100), discrepancy was observed in the criteria used to diagnose PCOS and not all included studies controlled for BMI which make the results non conclusive.

Contrary to the above studies, this study could not prove the association of PCOS with preeclampsia despite the higher prevalence of the condition among women with PCOS (3.1%) compared to controls (1.7%). This finding was in line with the findings on preeclampsia in a large study done on twin births of 226 women with PCOS diagnosis and compared to twin births of 20,742 women without PCOS through linkage between the Swedish Medical Birth Register and the Swedish National Patient Register (2015) (103). A possible reason to such finding in our study is the small numbers of the affected women with preeclampsia across the two study groups (n=34). Preeclampsia is considered an emergency situation that threatens the life of mothers and their newborns where patients usually present with very high blood pressure (<=140/90) and get treated before preeclampsia is developed. This small number of women who developed the condition might have made it difficult to detect the association if it had existed. Furthermore evidence suggests a link between preeclampsia and null parity (325-327) with the suggestion of the latter being a stronger predictor of preeclampsia than PCOS.

An increasing body of evidence suggests that insulin resistance in 50%-70% of women with PCOS is responsible for a state of hyperinsulinemia and thus the risk of glucose intolerance and GDM among these women (328, 329). It is worth mentioning that this excess insulin in women with PCOS is independent of women's BMI status(330). It is estimated that up to 40% of all women with PCOS will have developed type 2 diabetes or glucose intolerance later in life by the age of 40 years(331). Hyperinsulinemia is also believed to be associated with the risk of PIH in women with PCOS(330). Moreover the high prevalence of obesity commonly

observed among women with PCOS is believed to play a partial role besides PCOS in their risk to develop GDM and PIH(35).

Adverse birth outcomes

Our findings also support the association between PCOS and adverse birth outcomes namely; miscarriage, preterm delivery and undergoing emergency C-section among women with PCOS compared to controls. Women with PCOS were found to be 3.41 times (95% CI 2.23-5.22, p<0.001) more likely to have early pregnancy loss compared to controls. They were also 3.13 times (95% CI 1.61-6.10, p=0.001) more likely to deliver prematurely (before 37 weeks of gestation) when compared to the unexposed group. When mode of delivery by emergency C-section was examined, women with PCOS were 3.64 (95% CI 1.61-8.23, p=0.002) times more likely to undergo this mode of delivery compared to women without the disease. However no significant difference was found between the two groups when stillbirth was examined (OR 1.08, 95% CI 0.28-4.17, p=0.919).

The weight of available evidence points towards an association between PCOS and miscarriage among affected women. High proportion of women with PCOS (~50%) conceive undergoing ARTs such as the use of Clomiphene Citrate (CC), Follicle stimulating Hormone (FSH),Intra Uterine Insemination (IUI) and IVF (79) which are known for their risk of miscarriage regardless of PCOS status (332-336). However different studies that compared miscarriage between women with PCOS undergoing IVF and those without PCOS undergoing the same treatment to conceive, found higher proportion of miscarriage among women with PCOS (336-338).

However obesity is another prevalent risk factor for miscarriage among women with PCOS and women in general(131). A study by Wang et al. (2001) on 1018 women with and without PCOS undergoing IVF found 28% of those with PCOS undergo spontaneous miscarriage compared to 18 % of those without PCOS($p<0.01$). However, no significant difference remained between the two groups after adjusting for BMI in a multivariate analysis, suggesting the higher risk of miscarriage among women with PCOS was mainly due to higher prevalence of obesity among them rather than PCOS(132). Although our study could not assess the role of BMI on risk of miscarriage among women with PCOS, it was able to examine the independent role of PCOS on the risk of miscarriage adjusting for different modes of conception. This was not possible to conclude from the latter study as both study groups underwent IVF to conceive.

Two large studies (in USA (2012) and Sweden (2011)) examined the outcome of preterm delivery (<37 weeks of gestation) and found a positive association with PCOS after controlling for both BMI and ARTs (137, 138). In addition a meta-analysis (2006) involving 8 studies that have controlled for BMI found women with PCOS to be 1.75 (95% CI: 1.16 - 2.62) times more likely to have a preterm delivery compared to controls (107). This was in agreement with another meta-analysis by Qin et al. (2013) where the odds of preterm delivery was 1.93 times higher among women with PCOS compared to controls (95%CI 1.45–2.57)(82).

Our findings are in line with these studies where we controlled for both ARTs and multiple gestations and the risk of both miscarriage and preterm delivery remained higher among women with PCOS (OR 3.41 &3.13 respectively). Both ARTs and

multiple gestations are known independent risk factors for miscarriage and preterm delivery (339-343) suggesting the independent role of PCOS on these outcomes.

Evidence suggests hyperinsulinemia status observed in women with PCOS to be responsible for elevated values of plasminogen activator inhibitor-1 (PAI-1) whose serum concentrations are higher among women with PCOS than those of general population(344). PAI-1 is a glycoprotein and a potent inhibitor which interferes with fibrin cross-linking and regulation of fibrinolysis, a process vital for placental formation and thus successful pregnancy outcome(345). In addition several reports suggest high serum concentrations of LH hormone (>10 IU/L) (an additional common feature among women with PCOS) to be responsible as well for early pregnancy loss among women with PCOS (126, 346). Furthermore, studies demonstrated a role of hyperinsulinemia in the aetiology of inadequate blood flow to the endometrium leading to endometrial dysfunction and impaired implantation process (347-349). These factors among women with PCOS partially justify the higher rates of miscarriage and preterm delivery among this group of women independent of BMI and use of ARTs.

C-section was also examined within the adverse birth outcomes among women with PCOS in this study. However we opted to examine the prevalence of emergency C-section specifically as elective C-section is not considered to have the same burden on health resources to that of emergency C-sections, being most often unanticipated. Many studies have examined C-section in general as an adverse outcome among women with PCOS and found a positive association. A cohort study by Roos et al. (2011) on 3787 infants born to women with PCOS found

them to be more likely delivered by C-section (both elective and emergency) (OR 1.18 95% CI 1.07 to 1.29) compared to controls(138) and this was independent of BMI which is also considered an independent risk factor to delivery by C-section(139). Similar finding was concluded by a retrospective cohort study (2001) on 99 Finnish women with PCOS carrying singleton pregnancies where delivery by C-section was 2.1 times more likely among them compared to controls adjusting for BMI (CI 1.4–3.4; P <0.001) (111). In contrast, a study on twin pregnancies (2003) among women with and without PCOS found no difference between the two groups in the risk of C-section delivery (103). However the high likelihood of controls to undergo C-section as well might have masked the increased risk among women with PCOS had it existed as multiple gestation is a known independent risk factor for delivery by C-section(350). Reasons are not clear yet for why women with PCOS are more likely to undergo emergency C- section, as most studies considered this as a secondary outcome and it was not examined systematically.

Risk of stillbirth in women with PCOS was less studied in the literature due to its low prevalence in general(351). In addition, the small sample size in most of the current studies might have affected the power needed to detect it. However, similar to our results, findings among the studies that examined stillbirth as an adverse birth outcome did not find a positive association. A small cohort study on 52 Mexican women (2012) with PCOS found no association between PCOS and stillbirth when compared to controls matched for age, BMI and parity(102). Moreover a larger study (2011) on 3787 Swedish cohort of women also could not establish an association between PCOS and risk of stillbirth when compared to controls(OR

0.90,95% CI 0.50 to 1.63) (138). Due to the rare nature of stillbirth it might be best assessed using a case control study design instead of a cohort design.

Adverse newborn outcomes

Similar to this study findings, the majority of studies that have examined weight related outcomes among newborns to mothers with PCOS found a negative association between PCOS and both macrosomia(100) (141, 142) and LWGA (102, 138, 143, 320). Evidence relates macrosomia to GDM(352), a known metabolic feature prevalent among pregnant women with PCOS. However this study could not establish this association. On the other hand, a theory exists of hyperinsulinemia affecting the endometrium of women with PCOS including its blood flow making it an unsuitable environment for foetal growth (347, 349). This theory might suggest a higher risk of restricted foetal growth among these women and thus higher incidence of LWGA, but this could not be confirmed in many studies as mentioned above including this study. Further research showed an association between PIH and LWGA(353, 354), suggesting PIH might be a better predictor for LWGA than PCOS.

Despite the findings of newborns to mothers with PCOS to be more likely delivered prematurely and through emergency C-section, they were not found to be at a higher risk of having a low APGAR score nor more likely to be admitted in NICU compared to controls. Similarly a negative finding of low APGAR score was observed in a cohort study by Lovvik et al. (2015)on twin pregnancies among Swedish women with PCOS (n= 226) compared to twin pregnancies among controls (103). Another cohort study (2001) on 88 newborns to women with PCOS also could

not find a link between PCOS and both low APGAR and NICU admission when compared to newborns to mothers without PCOS(n=728) and adjusting for BMI and multiple gestations(111). Contrary to these results, studies with larger sample size related PCOS to adverse neonatal outcomes. In a large population based cohort study (2011) using the Swedish medical birth register between 1995 and 2007 and adjusting for BMI and ARTs found singleton newborns (n=3787) to mothers with PCOS having a lower APGAR score at 5 minutes after birth compared to controls (n= 1 191 336)(138). Similarly in a meta-analysis (2006) involving 720 women with PCOS found infants born to mothers with PCOS were 2.3 times more likely to be admitted to NICU than infants born to 4505 women without PCOS and this was unrelated to multiple births (OR 2.31; 95% CI: 1.25–4.26) (107).

The negative findings of our study on these newborn outcomes of low APGAR score and NICU admission might be due to the close monitoring of these high risk women and the advanced level of medical care offered to them in the highly specialized study hospitals. This might have prevented the possible perinatal complications. Moreover the majority of the prematurely delivered newborns to mothers with PCOS in this cohort were late preterm (16.2%) (>=32 weeks of gestation) compared to extremely (24-28 weeks) (2.4%) and very preterm newborns (28-32 weeks) (3.9%) who might be at a higher risk of having low APGAR score and being admitted in NICU for prematurity.

4.5.3 Strengths and limitations

Study population, size and design

Based on up to date published research, this is the first cohort study to examine reproductive health outcomes such as adverse metabolic, pregnancy and birth outcomes among pregnant women with PCOS in Oman and the Middle East and it is the first to further examine adverse health outcomes of newborns to these women. The available studies from Oman and the Middle East region focused mainly on PCOS prevalence and its physical and radiological characteristics (252, 255-258, 355). Findings from this study add an important contribution to the available evidence from other studies based in different places in the world, on the reproductive health of women with PCOS in Oman, given its comparable disease prevalence (7%) to that reported worldwide (252). Nevertheless evidence suggests higher prevalence of DM and GDM in general among Middle Easterners and Asians (356-359). Therefore examining such metabolic outcomes among women with PCOS compared with controls who are at similar high risk of developing these outcomes has strengthen the evidence of the obtained measures.

This study has included a total of 305 women with PCOS who comprised all the available and eligible cases of pregnant women with PCOS across the two study hospitals, recruited over 10 years period. This has powered the analysis given the small sample series (<100) reported in many of the currently published studies that examined the same reproductive outcomes (29, 34, 88, 101-103, 106). Furthermore using pregnancy rather than woman as a unit of analysis increased the sample size allowing to exceed the study's initial power calculation (chapter3, table 3.6, p 64).

Following, a cohort study design to conduct this research helped strengthen the evidence of the findings especially given that many studies around the world have examined these outcomes among women with PCOS mainly adopting a case-control study design. Cohort study design helped eliminate different types of bias including recall bias as the obtained data from hospital health records were originally prospectively recorded by healthcare providers. Moreover following a cohort design helped eliminate ascertainment of exposure status bias and investigator's bias commonly found in case control studies. In addition women with PCOS who conceive after use of ARTs are more closely monitored until delivery. However women without PCOS (study controls) are also followed up in the study hospitals in their third trimester and are screened for any metabolic outcomes during pregnancy along with complete documentation of peri- and post-natal conditions of mother and newborn given the high level of specialization of study hospitals. This has helped eliminate any ascertainment bias related to study's outcomes of interest.

Validity of exposure measures

Contrary to the published data on PCOS and reproductive health of women that suffered great heterogeneity in the criteria used to diagnose PCOS (108, 109, 133), this study followed a restricted methodology to select cases with PCOS. First, it restricted data collection to two tertiary hospitals that used the Rotterdam criteria to diagnose women with PCOS and eliminated a third tertiary hospital despite its fertility coverage to high number of women due to its use of mixed criteria in diagnosing the condition. Secondly, using specific ICD codes to identify women with

PCOS from the health records and double checking its absence for controls added to the validity of participant's exposure status. Furthermore, reviewing the presence and absence of the Rotterdam criteria components for cases and controls respectively provided a robust assessment of the sensitivity and specificity of the coding system and thus further eliminated classification bias. PCOS is considered an underdiagnosed condition among women of reproductive age (12),therefore it is likely for it to have been present among the controls in this study and thus could not be excluded from the analysis. If this was true then it indicates that the obtained effect measures are underestimated and the likelihood of PCOS to be associated with the outcomes of interest in this study is larger than what has been detected.

Missing covariates

Carrying out the study retrospectively led to a potential limitations of incomplete data on participants' weight recordings especially during early pregnancy (during the first trimester), as it is believed that weight measurement at this stage of pregnancy is a more accurate determinant of its effect on different pregnancy outcomes. Pregnant women with PCOS are considered as high risk patients and because the majority conceive after use of ARTs, they are followed up in the hospital early during pregnancy and more frequently until delivery allowing for a more complete and early weight recording during pregnancy compared to controls. Controls normally will start ANC visits in the local HCs and will be seen in the hospital only after 32 weeks of gestation for the third trimester follow up and thus

delivery, allowing for weight recording to be measured only around this time of gestation.

Descriptive analysis of the available weight recordings showed women with PCOS had higher mean weight recordings along the three trimesters of their pregnancies compared to women without PCOS. However, the calculated BMI of the available weight recordings in the first trimester showed the majority of women with PCOS and without PCOS were in the "overweight" category (37.8% & 38.6% respectively). Therefore BMI might have not been very different between the two groups in the first trimester and thus the obtained results might not have been affected from not accounting for BMI in the analysis. Overweight and obesity are common among Omani women in the reproductive age given the high fertility rate among them(360). However higher proportion of women with PCOS were "obese" and "morbidly obese" (31.1% & 25.2% respectively) compared to those without PCOS (26.8%&13.6% respectively).

Although high BMI is a known factor to influence metabolic and pregnancy outcomes, some studies found a positive association between PCOS and these outcomes after controlling for BMI, suggesting the independent role of PCOS on these outcomes (111, 138, 361).

Many of the previous studies have discussed lack of BMI recordings and therefore the failure to adjust for it in the analysis as a limitation. However BMI is arguably considered as an intervening variable and on the causal pathway rather than a confounder. If this is true then BMI should not be adjusted for statistically, as by doing so we might be taking away the very effect that we are trying to

demonstrate(362). Unfortunately there is no statistical test to help decide whether BMI is a confounder that should be included in the adjustment or an intervening variable that should be excluded. The decision should be made based on prior research or biological plausibility. The majority of the studies that have looked at these associations have considered BMI as a confounder. While some studies proved the associations between PCOS and many of the outcomes of interest controlling for BMI (111, 138, 361), few others failed to do so and thus related these outcomes to the high BMI rather than to PCOS itself(110, 137). On the other hand studies on lean individuals with PCOS has also established an association between PCOS and the metabolic outcomes of interest (40, 41). This might suggest an independent role of PCOS on these outcomes and possibly a synergistic effect of high BMI. Therefore the role of high BMI in women with PCOS on the various reproductive outcomes needs to be analysed more carefully and systematically in future studies to decide whether it has a compounding or a mediating effect on these outcomes.

Moreover, in this study an attempt was made to include family histories of DM and HTN as possible confounders to the association between PCOS and study outcomes. However these variables suffered considerable proportion of missing data as this information is not routinely collected during women's ANC follow ups, therefore the results obtained from their inclusion in the analysis were not acceptable as it was calculated only for roughly 10% of study's sample and therefore were not presented in this study. However we controlled for some of the other important confounders such as educational level, employment status, women's age, women's gravidity and parity status, use of ARTs and accounting for clustering effect

presented by the hospital of study, women and multiple gestations which helped strengthen the evidence of the obtained findings.

Moreover the minimally missing data on outcomes of interest was probably related to excluding participants with loss of follow up from the study sample. However the missing data on the other important demographic and obstetrics characteristics of participants were also minimal reflecting the good level of information documentation process by healthcare providers in the study hospitals.

Generalization of study findings

The conduction of the study in two hospitals based in the city of Muscat, makes the representativeness of the selected participants to the general population and thus generalizability of study's findings questionable. However the selected hospitals are major tertiary hospitals in Oman that get referrals from almost all over the country. In addition many people living in the capital city of Muscat chose their place of residence for the commuting convenience, being employed in its institutions and travelling back to their home cities over the weekends. Moreover a hospital based prevalence study of PCOS in SQUH showed women with PCOS are visiting from all the 7 governorates of the country(252)and it is reasonable to believe this applies to the RH as well with its larger pool of patients given its more public remit compared to SQUH.

4.5.4 Conclusions and clinical implications

This study provides evidence of women with PCOS being at an increased risk of developing GDM and PIH during pregnancy and their higher risk of having early pregnancy loss, premature delivery and undergoing emergency C-section. Healthcare providers should warn pregnant women with PCOS about their risks to develop these adverse metabolic and birth outcomes. Vigilance, antenatal surveillance and monitoring should be applied to these women to prevent the higher cost of the long-term consequences of these outcomes (145, 265-267).

Moreover, this study showed women with PCOS were generally heavier when their weight was compared to controls during the gestational time and obesity is a known factor for many adverse outcomes during pregnancy, therefore pregnant women with PCOS who are with high BMI should be strictly advised about weight reduction early when they plan to conceive to minimize the other known risks associated with it (363-365)beside the risks associated with having PCOS as they have been detected in this study.

The results of this study provide reassuring evidence that live neonates born to mothers with PCOS are not at an increased risk of adverse neonatal outcomes soon after delivery compared to controls. However the risk of them being delivered prematurely, particularly at “extreme” and “very preterm” stages, should be considered by healthcare providers who should cautiously look for signs of early labour and provide appropriate advice to the affected patients to enable early intervention and prevention of further complications(366, 367).

Further studies should be conducted in the region, including participant's BMI in the analysis to help understand the extent of the independent role of PCOS on various reproductive outcomes or whether these risks are compounded by high BMI among women with PCOS who are overweight or obese. Studies should also be conducted to understand the reasons behind the increased likelihood of pregnant women with PCOS to undergo emergency C-section as this has not been systematically examined before. This will help healthcare service providers to better utilize resources to avert the cost of these most often unanticipated interventions.

5 The psychosocial effects of infertility among Omani women with PCOS and their satisfaction with healthcare services in fertility clinics

This chapter presents the experiences of infertility among women with PCOS in Oman. First, women's psychosocial experiences of living with infertility was considered in the Omani culture. Second, womens' experiences with healthcare services, including treatment and care they have received in fertility clinics was addressed. In particular, the extent to which emotional support was offered to them by healthcare providers was explored.

5.1 Introduction

Women with PCOS have higher than normal androgen hormone levels(12). Androgen hormone is also known as the "male hormone" and it is responsible for male characteristics such as alopecia, excessive hair growth and muscle mass(3). These high levels of androgen among women with PCOS leads to irregular menses or anovulation, which makes it difficult for these women to get pregnant and therefore a large proportion of them experience infertility(368). Infertility is defined as the inability of a couple to conceive after 12 months of unprotected sexual intercourse(153). Anovulation due to PCOS is considered the most common cause of infertility in women, accounting for 75% of infertility cases(84).

5.1.1 Women's experience of living with PCOS and its symptoms

Many qualitative studies on PCOS have mainly studied the effects of its symptoms including hirsutism, acne, alopecia, obesity and infertility on the lives of affected women. In the UK, Kitzinger et al. used thematic analysis to evaluate the symptoms of PCOS among 30 women. These women reported feeling 'freakish', abnormal and not 'proper' women due to the prevalent male like symptoms including infertility which was one of the three main symptoms experienced by these women(208). Similarly, a study conducted with Iranian women with PCOS reported women feeling inferior, ashamed and of impaired femininity compared to other women, mainly due to their infertility and menstrual disorders(369). The impact of these feelings could be profound. For example, interviews with 10 English women with PCOS revealed the occurrence of self-harm and suicidal ideation(368) . The need for HCPs to support this group has been advocated, in order to address both the physical and psychological symptoms of affected women(370).

The high levels of masculinizing hormones among women with PCOS suggest triggering psychological burden among these women. A number of systematic reviews and meta-analyses support this view. Findings from Bary et al. who examined a series of studies highlighted that women with PCOS scored higher for anxiety and stress disorders compared to non-PCOS women(371). Another study by Veltman-Verhulst et al. also showed that women with PCOS exhibited more psychological distress compared to other women(372). Moreover, a recent systematic review by Cooney et al. who surveyed 30 studies of 10 different countries, proved PCOS to be an independent risk factor for increased psychological

burden, namely depression and anxiety(373). Other studies have also supported the increased psychological burden among women with PCOS compared to other women, in a number on non-Western populations such as Turkey, Taiwan and Pakistan (374-376). A recent study in Oman examined the magnitude of psychological disturbances and their correlates among 52 women with PCOS using the Depression, Anxiety and Stress Scale (DASS-21) and indicated that the presence of PCOS was associated with an increased risk of psychological burden compared to controls(259).

The pathophysiology of PCOS provides a possible explanation of the observed psychological burden among these women, as the increased levels of insulin and androgen change monoamine balance which is responsible of the observed mood disturbances among women with PCOS(377).

Studies have also suggested that the psychological burden among women with PCOS might arise from the social impact of its symptoms on the affected individuals. The anti-feminine symptoms common among these women due to high androgen levels affect their body image and feminine identity in the society and therefore trigger psychological burden(378-380) among these reported symptoms is their inability to bear a child(259).

5.1.2 Psychosocial aspects of infertility

According to several anthropological studies, the personal and social implications of infertility is strongly related to the religious and/or cultural background of affected women(381-386). PCOS is among the most common endocrine causes on infertility among women of reproductive age(387) which itself shows a wide range of

symptoms that affect women's identity including infertility(388). Failure of these women to conform to idealized 'feminine' norms of appearance and behaviour explains the increased levels of stress and anxiety among them(207, 389-392).

Quantitative studies on psychosocial consequences of infertility from various causes (not PCOS specifically) among Western populations reported symptoms of depression, stress, anxiety, marital and social adjustments, low self- esteem and loss of control(393-397). In contrast, studies that have tried to understand the experience of infertility among African women and couples tended to be more qualitative in nature(398). These studies reported involuntary childlessness to be responsible for marital instability, divorce, loss of social status, abuse, poverty and stigmatization(178, 191, 391, 399-401).

5.1.3 The experience of infertility among women due to PCOS

To date few studies have tried to understand the effects of infertility specifically among women with PCOS. These studies are quantitative and used standardized questionnaires and reported inconsistent findings. A study carried out in the United States assessed 97 adolescent girls with PCOS using Child Health Questionnaire Version CF-87, as a measure of health-related quality of life. Results showed girls with PCOS were 3.4 times more likely to be worried about their ability to become pregnant than their healthy counterparts and concerns about future fertility was associated with significant reductions in quality of life(402). Similarly, a study by Schmid et al. among Austrian and Muslim immigrant women in Austria used the Cronin's health-related quality of life questionnaire and reported infertility to be a dramatic problem for immigrant women(204). The Muslim immigrant women with

PCOS suffer more from infertility compared to Austrian women as they experienced high pressure to reproduce, emphasizing the ethnic, religious and cultural differences among affected women that warrants consideration by HCPs(204). This was in line with a study in Germany to assess the quality of life, psychosocial wellbeing, and sexuality of 50 patients with PCOS and controls (n=50) with three standardized, validated questionnaires, which found PCOS causes a major reduction in quality of life and severely limits sexual satisfaction, and this partially attributed to their infertility(205).

However, in a study in Germany on quality of life in 115 women with PCOS, the majority of participants (76.1%) worried about remaining childless in the future, and 51.3% reported a wish to conceive; despite these admissions infertility did not appear to constitute a primary determinant of psychological problems among these women(206). This was consistent with the findings of a study in the USA that compared 40 women with PCOS to women with infertility but not PCOS, and to women with neither PCOS nor infertility, on measures of depression and body image. Results found women with PCOS reported higher depression scores and greater body dissatisfaction, mainly due to body image issues rather than infertility(403).

To the best of the researcher's knowledge, no studies have solely focused on infertility and its psychosocial aspects among women with PCOS using qualitative methods. It might be assumed that the experience of infertility among women with PCOS in a defined population would be similar to other women's experiences, regardless of the cause of infertility. However, since qualitative studies on women's

experience with PCOS symptoms report them feeling less feminine than other women(10, 22), infertility might have a different impact on them given the sociocultural background of the region where the literature on the psychosocial experience of infertility (regardless of the cause) is scant(404-406).

5.1.4 Experiences with infertility management: Patients' perspectives

Infertility regardless of its aetiology is considered more than just a medical condition; it affects a woman's social, psychological and sexual lives(219). Seeking treatment for infertility has shown to increase the emotional burden among couples especially women who were found to be more psychologically affected from infertility and its treatment compared to men(407, 408). PCOS is reported to be the most common endocrine disorder to cause infertility among women(409) and thus it is estimated that majority of those seeking fertility treatment are women with PCOS. A large population based cohort study of women seeking fertility treatment in Australia reported that 62% of the infertile women comprising their sample were affected by PCOS, compared to 38% of those who were infertile due to other causes(410).

Recently the field of fertility care has focused mainly on techniques to achieve better outcomes in fertility management(411). However, the dimension of patient-centred care which includes access to care, continuity of care, involvement of family and friends and emotional support, physical comfort and respect of patients' references is neglected(412).

The studies that examined patients' overall experiences of fertility treatment, namely encounters with fertility HCPs found them giving attention to both system and human dimensions of care(231, 413). System factors were: provision of information, competence of clinic and staff, coordination and integration, accessibility, continuity and transition and physical comfort. While human factors, were: attitude of and relationship with staff, communication, patient involvement and privacy and emotional support(231, 414).

Furthermore, another study was conducted in the Netherlands which administered a questionnaire among 1,499 infertile women in 16 fertility centres assessing the determinants of patients' experiences and satisfaction with fertility care. It reported that waiting times, information provision and emotional support were experienced as the least positive aspects of care(415).

Evidence suggests that improving patient's experience with fertility care and removing the physical and emotional burden among patients might eventually contribute significantly in hormonal balance and treatment success(415). Furthermore, literature has shown that there is a strong correlation between the experiences of patients and staff. A higher level of patient-centeredness care contributes to a higher level of professional satisfaction among nurses and physicians(416, 417).

On the other hand, studies that have examined the dropout rates among patients seeking fertility treatment and who were financially secure found it to be mainly due to their inability to bear the physical and emotional burden of infertility treatment(215, 418, 419). Therefore, attention should be directed to offer

emotional support to patients seeking fertility treatment given its highly stressful and exhaustive nature.

In a qualitative study conducted in Denmark with 16 couples undergoing infertility treatment, Schmid et al. assessed couples' experiences with infertility treatment and found they were dissatisfied(420) . This was mainly due to the lack of psychological counselling provided given the psychological strain of fertility treatment. Couples also lacked detailed information about the technical aspects of infertility and its treatment(420). Another study by Van Den et al. Which was conducted in Belgium and involved 9 women who dropped out of fertility treatment, did so due to the high psychological burden of infertility treatment (220).

5.2 Study rationale

To the researcher's knowledge there is no previous qualitative study that has focused solely on the psychosocial effects of infertility among women with PCOS. Available qualitative studies have examined affected womens' experiences with PCOS symptoms in general. Moreover, the psychosocial impact of infertility regardless of its cause is a neglected research area in Arabic and Islamic region, where only a few qualitative studies were found in the literature(404, 405, 421). There are expectations and pressure for women to get pregnant once they are married in the Arabic culture(386, 421), which makes infertility an issue of huge concern. The social pressure and stigma associated with a woman's inability to conceive(405) may push these women to seek medical care to achieve this goal. At the same time it suggests they are likely to have psychological consequences that

need to be identified and addressed by HCPs; however the extent to which their psychosocial wellbeing is being considered and supported is unclear. Therefore, the cultural and contextual experience of infertility among women with PCOS is an important issue to explore in these countries. These women's experiences with infertility due to PCOS in the Omani culture might be different to other women's experiences (due to other causes) elsewhere, due to the dominant male like symptoms that are common among them. Moreover, understanding the psychosocial experience of infertility in the Omani culture is one of the priority research areas set out by the Ministry of Health in Oman. Findings from this study will be of a great relevance to help HCPs establish strategies to counsel and support this group accordingly.

5.3 Study aims

This study aimed to understand the lived psychosocial experience of infertility among women with PCOS in Oman and to explore their satisfaction with the received healthcare services in fertility clinics including the extent to which emotional support is offered.

5.3.1 Study objectives

1. To explore the psychosocial effects of infertility among Omani women with PCOS.

2. To explore women's satisfaction with the healthcare services received in infertility clinics.

3. To explore the extent to which HCPs offer emotional support to women in fertility clinics.

5.4 Methods

5.4.1 Study settings

Infertility services in Muscat - Oman are offered within the department of obstetrics and gynaecology located in two tertiary centres namely Sultan Qaboos University Hospital and Royal Hospital. These services are also available in two polyclinics; Bowsher and Wattaya. Other regional hospitals In Oman located in the different cities outside Muscat also offer limited infertility services including diagnosis and first level treatment of infertility, which includes induction medications only. These services are available for no extra cost other than the annual fee of Omani Rial (OR) 1.200 (£1.96) paid by citizens to access the national health services in general and a co-payment of OR 0.200 (£0.39) at each visit.

Access to governmental specialized fertility clinics in Muscat is obtained through a referral system either from the local HCs, the private fertility clinics or the other countrywide regional hospitals that lack the more advanced services available in the fertility centres in Muscat. Fertility services available in the tertiary centres include diagnostic procedures such as hormonal blood tests, radiological imaging of women's reproductive organs, diagnostic/therapeutic laparoscopies and men's semen analysis test.

Fertility management is limited to first and second levels of treatment in these centres. First level treatment includes treatment with fertility medications including oral and gonadotropins only. Second level treatment includes fertility medications and intra uterine insemination. The third level of treatment is ARTs including In Vitro Fertilization (IVF) and Intra Cytoplasmic Sperm Insemination (ICSI)

(317), which are only available in private specialized fertility centres, due to their high cost.

However, fertility clinics in government hospitals liaise with private fertility centres to do all the required blood and radiological tests and the induction medications for patients, before they go for the ARTs. Government clinics also follow up and monitor patients with successful implantations. These steps help reduce the burden of costs upon couples going through ARTs.

All undertakings at these clinics comply with Sharia Law/Islamic rules and regulations as interpreted and implemented in the Sultanate of Oman; for example, it is prohibited to use donated sperm or eggs from other than that of the married couple, as this leads to a mix in family's lineage(317).

5.4.2 Study design

This study adopted a qualitative design and it involved infertile Omani women, with PCOS as the cause of infertility. A constructivist philosophical approach underpinned this study as it allowed the researcher to gain an understanding of the lived experience of infertility of Omani women with PCOS from their own perspective(138)(see chapter2). A semi-structured interview guide was used to conduct one-to-one interviews (as discussed in chapter 2).

5.4.3 Study population, sample size and recruitment

Married infertile Omani women of reproductive age (15-49 years) with diagnosed PCOS as the cause of their primary or secondary infertility (have had a pregnancy before but with no previous live births) were targeted. Women were recruited from

infertility clinics from the two study hospitals (SQUH and RH) where the quantitative studies comprising this thesis were conducted. A total of 20 women (10 from each infertility clinic in the two selected hospitals) were interviewed (see chapter 2, section: Methodological considerations in qualitative research, p 51, for sample size selection justification). The obtained data attained saturation level, where no new themes were identified following preliminary analysis; therefore, recruitment of participants did not continue beyond the 20 selected participants.

First, the researcher obtained lists of women (fulfilling the criteria in Table 5.20) scheduled to attend the infertility clinics over the period from June 2018 to August 2018. Participant selection was based on a purposive sampling strategy (see chapter 2 on purposive sampling, p 52) to ensure a variety of women were interviewed. Recruitment included women of different age groups, duration of infertility and duration of infertility treatment, to ensure brevity and depth.

Women meeting the study inclusion criteria (Table 5.20) were identified from the clinic appointment lists one week before their appointment. The researcher first contacted the eligible women via telephone and briefed them about the study and invited them to take part, prior to their hospital appointment. The study information sheet was emailed to participants who were willing to read more about the study, while others were happy to read the study information sheet on the day of the interview prior to interview commencement. This sheet included information on the purpose of the study, reason why they had been approached, advantages and disadvantages of their participation and information to enable them to contact the researcher (Appendix F1). Eligible individuals that were unreachable via phone

calls after several attempts or due to changing their telephone numbers were approached in the clinic (prior to their clinic's appointment), and were handed the information sheet and interviewed as per their reference either on the same day or at a later agreed appointment.

5.4.3.1 Inclusion and exclusion criteria

Table (5.20) shows the inclusion and exclusion criteria for the selection of study participants from the two fertility clinics.

Table 5.20: Inclusion and exclusion criteria for the selection of patients with infertility and PCOS

Inclusion criteria	Exclusion criteria
• Omani • Married and in the age group (15-49) years • Diagnosed with primary or secondary infertility (with no living children) due to PCOS • Current follow up and have had previous follow ups in fertility clinics of study hospitals	• Foreigner (non-Omani) • Secondary infertility with living children • Cause of infertility other than PCOS • Attending fertility clinic for the first time at time of interview

5.4.4 Data collection

A semi-structured interview guide was developed based on the literature review and study objectives. This was the best method to ensure getting the most out of interviewees on a given topic, as suggested by Bernard (1988)(297)(see chapter 2,p 51 ,section: Methodological considerations in qualitative research) . The guide

included open ended questions on the following areas: psychological impact of infertility, social perception of infertility, coping strategies with infertility and satisfaction and experience with health services and the consultation process in fertility clinics, including the extent to which emotional support was offered (Appendix F3). At the end of each interview, the researcher collected basic demographic information from the participants, such as participant's age, educational and employment status, place of residence, number of years since marriage, number of years experienced infertility, number of years since fertility treatment started, whether they had conceived before and number of previous abortions, in case they had conceived previously.

Interviews were participant-led, where the researcher followed up aspects discussed by the individuals accordingly. This approach helped the interviewee to better express their experience and perspectives leading to a better narrative and thus richer data(422). The interviews were digitally audio-recorded. All interviews were conducted in a private, quiet room in the fertility clinic either before or after patients' appointments. Participants were given a consent form to sign before interviews commenced (Appendix F2). The consent form provided information on data confidentiality where participants were informed that they would be given a unique study code and that personal information would be anonymised. Participants were also informed that data would only be accessible by the research team including the external translator/transcriber. Information was also provided about data to be stored on a password-protected computer and archived in the University of Nottingham for two years after the completion of the study as per the University's regulations.

Of the 23 approached patients, 3 could not take part in the study, due to time constraints (n=2) and transport related reasons (n=1). These individuals were not keen to have the interviews conducted outside the hospital setting, when this option was offered. Interviews lasted 47 minutes on average and ranged from 29 minutes to 68 minutes. All interviews were conducted in Arabic, as requested by participants.

5.4.5 Ethical approval

Ethical approval was obtained from the two hospitals. Approval for Sultan Qaboos University Hospital was obtained from Sultan Qaboos University Medical Ethics Committee for SQU hospital (Appendix E1). Ethical approval to recruit from Royal Hospital was obtained from the Ministry of Health-Research and Ethical Review and Approve Committee-Directorate General for Planning and Studies (Appendix E2). Ethical approval was also obtained from the University of Nottingham's Medical School Ethics Committee (Appendix E3).

5.5 Analysis

5.5.1 Framework analysis

Qualitative data were analysed using the framework approach. Framework analysis is a systematic method for managing qualitative data, where the generated codes along with the summarized data are charted to allow interpretation and synthesis (72). Framework is a flexible analysis tool that can be used to generate themes irrespective of the epistemological, philosophical or theoretical underpinnings of

the research (423). Framework offers a systematic way of analysing qualitative data as it produces a highly structured data output to enable researchers to constantly compare and contrast the different views and experiences of participants to come up with interpretive concepts that describe aspects of data called “themes”(423).

The researcher followed the 6 steps suggested by Gale(423) to analyse the collected data. First, translation and transcription: since the interviews were conducted in Arabic, they were first translated and transcribed verbatim in English through an external source. Translation and transcripts were checked against audio-recordings by the researcher, to ensure that they were accurate. Transcripts were exported into Nvivo 11 software to facilitate data management and analysis. The second step was familiarization with data. Although the interviews were conducted by the researcher, the transcription was completed by an external source, thus the researcher checked the final transcripts and when necessary listened back to the audio-recordings to get immersed into the data. Third, as part of the coding process, the researcher carefully went through each line of the transcripts and assigned codes that described the concluded interpretation from that passage. This was exercised using an inductive approach i.e. trying to code anything that might present patient’s experience with the phenomenon under study, including their narrations of their actions, behaviour, assigned values, feelings and so on, to make sure not to miss anything. This was initially completed for 10 data-rich transcripts. The same set of 10 transcripts were independently coded by an experienced qualitative researcher (academic supervisor), to allow for alternative viewpoints and to ensure the generated themes were valid. The fourth step was to develop a working analytical framework. The identified codes were compared between the

researchers and modified to include all viewpoints and further grouped into clearly defined categories “Themes”. Fifthly, applying the analytical framework, where the researcher continued assigning the agreed codes on the rest of the remaining transcripts but also noting any new codes during this process. Data saturation was believed to have been attained using the selected sample size as very few new codes were generated in coding the rest of the remaining interviews(424). The final version of codes and themes was agreed upon by both researchers, following complete analysis of the entire set of transcripts. Because the researcher opted to do the initial coding on paper, indexing in Nvivo was completed following the final generation of codes. This facilitated storage and organisation of the data and made it easily retrievable and accessible during the analysis process. Finally, the data was charted into the framework matrix. This step involved charting summarized data for each code/theme from each transcript into a spreadsheet, in a word document (matrix) (Appendix G 1-8). This process was done carefully to retain the original meaning of data while reducing the size where applicable. Some quotes from participants were inserted into the matrix.

5.6 Results

5.6.1 Participants demographics

Table (5.21) summarises the demographic profiles of the 20 study participants. The average age of women was 28 years (range from 19 – 35 years). Most women were from the region of Muscat (n=7, 35%). Half of the women were in employment and the majority of them had a high school education or a higher educational degree (n=17, 85%). The average number of years participants reported trying to conceive was 4 years, and this ranged from 1 year to 12 years period. These women reported receiving infertility treatment for the same length of time. Only 5 (25%) of the participants had conceived previously, but these ended in miscarriage.

Table 5.21: Demographic characteristics of 20 women with infertility

Patient study ID	Age	Residence	Employment status	Educational level	Years of marriage	Years trying to conceive	Conceived before	No. of Times conceived	Years of fertility treatment
SQUH1	22	Sumail	Yes	primary	7	7	No	-	7
SQUH2	31	Mudhaibi	Yes	Bachelor	10	8	Yes	1	8
SQUH3	32	Wadi bani khalid	No	High school	12	12	Yes	1	12
SQUH4	22	Muscat	No	Bachelor	3	3	No	-	3
SQUH5	19	Nizwa	No	High school	1	1	No	-	1
SQUH6	27	Sumail	Yes	Bachelor	5	3	Yes	2	3
SQUH7	25	Fanja	No	Bachelor	2	2	No	-	1
SQUH8	30	Muscat	Yes	Secondary	4	3	No	-	3
SQUH9	28	Muscat	Yes	Bachelor	3	3	No	-	2
SQUH10	28	Rustaq	No	High school	5	5	Yes	2	5
RH1	32	Rustaq	Yes	High school	6	6	No	-	6
RH2	28	Nizwa	No	High school	4	4	Yes	1	3
RH3	27	Rustaq	No	High school	2	1	No	-	1
RH4	33	Muscat	Yes	High school	3	3	No	-	3
RH5	35	Musanah	No	High school	10	9	No	-	9
RH6	34	Muscat	Yes	Diploma	4	4	No	-	4
RH7	24	Rustaq	Yes	Diploma	4	3	No	-	3
RH8	30	Barka	No	Bachelor	3	3	No	-	3
RH9	25	Muscat	Yes	Bachelor	2	2	No	-	1
RH10	31	Muscat	No	Primary	10	10	No	-	8

5.6.2 Qualitative findings

Eight core themes were identified each with corresponding sub-themes, across participants' interviews (Appendix G). These are summarised in table (5.22) and will be discussed in detail below, with supportive extracts throughout.

Table 5.22: Main themes and sub-themes emerged from interviews with women with PCOS and infertility

Main Themes	Sub-Themes
1. Self-perception of infertility	**1.1 The role of hopefulness, religion and spirituality** 1.1.1Hopes of conceiving 1.1.2Faith in God's will **1.2 The impact of infertility on participants' emotions** 1.2.1Loneliness 1.2.2 Jealousy 1.2.3 Sorrow and sadness 1.2.4 Inferiority 1.2.5 Guilt **1.3 Fears and concerns about infertility and its consequences** 1.3.1 Not to experience motherhood 1.3.2 Concerns around chance of conceiving reducing with increasing age 1.3.3 The impact of infertility on couple's relation
2. Cultural aspects around infertility	**2.1 Beliefs around child bearing** 2.1.1 Infertility is always attributed to the woman 2.1.2 Infertility is caused by envy and an evil eye

3. Living with infertility	**3.1 Social pressure and expectations** 3.1.1 Comparisons with other couples 3.1.2 Frequent questioning 3.1.3 Judgemental comments **3.2 Coping mechanisms** 3.2.1 Husband's support 3.2.2 Self-distraction 3.2.3 Social adjustment 3.2.4 Adopting a healthy lifestyle 3.2.5 Coping gets easier the longer you experience infertility
4. Adoption in the Omani community	**4.1 Society's views on adoption** 4.1.1 Adoption is forbidden in Islam 4.1.2 Rejection of whom these children are 4.1.3 Confirmation of couple's sterility **4.2 Women's views on adoption** 4.2.1 Limitations in raising adopted children 4.2.2 Lack of real compassion towards adopted children 4.2.3 Exposing adopted children to unfavourable social situations
5. Access to governmental fertility centres	**5.1 Shift from private clinics to government clinics** **5.2 High expectations accessing tertiary governmental clinics**
6. Communication with HCPs	**6.1 Lack of information about medical condition and clinical procedures** **6.2 Language barrier**

	6.3 Nurses' limited role **6.4 Gender barrier** **6.5 Short consultation time**
7. Professional emotional support	**7. 1 Lack of professional emotional support** 7.1.1 Limited consultation time 7.1.2 HCPs want to avoid embarrassing the patients 7.1.3 The focus is to treat the organic cause **7.2 Emotional support is a HCP's personal choice** **7.3 The need for emotional support** 7.3.1 Negative feelings from social pressure 7.3.2 Burdened with infertility treatment 7.3.3 Positive experience and impact around discussing emotional wellbeing and support
8. Experience with fertility care service and HCPs	**8.1 Lack of continuity of care** **8.2 Lack of experience among HCPs** **8.3 Gaps in clinic set up**

5.7 Theme 1: Self-perceptions of infertility

Interviews with women revealed different ways in which infertility and delays in conceiving had affected their personal lives and relations with their partners. Women used self-comforting techniques to accept and cope with their infertility,

which centred around religious and spiritual beliefs, which seemed to lift their spirits and keep them motivated and positive about fertility treatment and the chances of success. However, participants were honest in sharing their fears and concerns around not being able to conceive. Women also discussed the consequences of infertility on the experience of emotional and marital relationship stress, as a result of being unable to conceive (Appendix G1). Each of these sub-themes will be discussed in turn.

5.7.1 The role of hopefulness, religion and spirituality

5.7.1.1 Hopes of conceiving

Most of the participants shared their hopes of conceiving, and that it was this that motivated them to adhere to their fertility treatment, despite its failures and challenges. Adopting a hopeful mind-set helped motivate participants to seek solutions for their infertility:

> *"I think a lot about the treatment and where we can find it...even if I know that treatment will be at the end of the world, I will go there and will pay money to receive it no matter what"*
>
> **(28 yrs. 4 years of infertility)**

Being hopeful helped lift their spirits and take them out of misery. Those who had experienced infertility for a shorter period of time (<2 years), seemed to be more hopeful because they perceived themselves as having a better chance, given their younger age:

"I am still young and I have just started my life recently and still have enough time to do many things...I know that these problems are within normal range so I am not afraid of not having children in the future..."

(19 yrs. 1 year of infertility)

Another 25 year old participant with 2 years of pregnancy delay said:

"My main concern wasn't the pregnancy itself because I am still young and still studying so it is normal if I stayed two years without pregnancy...and I will carry a pregnancy hopefully"

Participants who experienced miscarriages used hope as a way to forget their painful experiences and move forward:

"The whole process of intra uterine insemination (IUI) failed again after the previous abortion and then we said let us take another rest from treatment, but we still have a hope in this life and will continue seeking treatment"

(25 yrs. 2 miscarriages)

Participants were seen to compare their infertility condition with other women with infertility. Being infertile due to PCOS and relatively shorter duration of time compared to others who were diagnosed with more difficult causes of infertility or had it for a longer duration of time (15-20 years), helped give them much of the hope needed to be more patient and pursue fertility treatment. A 27-year-old participant with a pregnancy delay of 3 years but who succeeded to carry a pregnancy that ended with a miscarriage said;

"One of them is my work colleague and she got pregnant after she has waited for 13 years and during that period she took all treatments and wasn't successful. So, I was thinking about myself that after the first treatment session I got pregnant..so I felt that I have a good chance"

(27 yrs. 3 years of infertility)

5.7.1.2 Faith in God's will

It appeared that participants were also strongly using their faith in God and referring to 'God's will' to help them through their experiences of infertility, which seemed to serve to comfort them and help them to cope. Although women revealed having hopes to conceive one day, many strongly believed that having children might not be in their destiny. They believed that God is generous and will grant them children if he wishes to and if not then that might be best for them and they would be satisfied. A participant mentioned:

"I am leaving it entirely to Allah (God) and will let him protect us and decide for us...I mean are we going to run away from Allah's destiny?!"

(28 yrs. 3 years of infertility)

Women reported finding strength to go through childlessness by getting closer to God and by practising certain religious activities such as prayers, reciting verses of the holy Quran and asking for God's forgiveness for any sins. Participants felt that engaging in these practices would help to ensure that their prayers are answered, and that they are granted children.

"I pray to Allah to give us children, we will keep holding the hope all the time, I'm always reciting Quran and do my prayers, especially Surat Albaqarah (specific verses of Quran). I read it every day and night and we are always optimistic"

(32 yrs. 12 years of infertility)

5.7.2 The impact of infertility on participants' emotions

Among the consequences of infertility as perceived by participants, were a number of mixed emotions commonly experienced by them (Appendix G1). These are further discussed below.

5.7.2.1 Loneliness

A common feeling relayed by women was the feeling of loneliness. These women report suffering from boredom as they do not have children to keep them busy and that this has affected their relation with their husbands in a negative way. Some women went on to state that their houses felt lifeless and empty and as such they took up various activities or spent time with their family.

"I go out in the afternoon after work as I don't want to stay at home alone because it feels so quiet and empty, so I like to go walking or spend time in my family house"

(30 yrs. 4 years of infertility)

Some women also believed that this emptiness made their husbands find ways to escape from being at home.

"We can feel that our house is depressive because it is only two persons who live in it and it is very quiet all day; as a result, my husband is not interested to stay at home and he likes to go out and spend time with his friends...and I feel so lonely most of the time"

(22 yrs. 7 years of infertility)

5.7.2.2 Jealousy

Half of the participants had feelings of jealousy towards pregnant women. Some reported feelings of envy towards pregnant women especially those who get pregnant despite getting married after them:

"I know that most girls who are younger than me have children now and anyone who gets married will soon get pregnant within two months, I envy them"

(28 yrs. 3 years of infertility)

Feelings of jealousy were also apparent towards women who already had children, but that they tried to console themselves with thoughts about the role of destiny.

"Sometimes when I see someone has a child and I don't, I feel annoyed and jealous but I say again that it is my destiny"

(27yrs. 2 years of infertility)

Other women were more jealous when their husbands were interacting with other children.

"So I get annoyed and jealous when I see my husband is playing with babies"

(27 yrs. 5 years of infertility)

5.7.2.3 Sorrow and sadness

More than half of the participants mentioned feelings of sorrow and sadness around their infertility. Feelings of sadness among these women normally stemmed from the external pressures they faced, most often from family and work colleagues questioning why they had not become pregnant or had children yet. Some participants described feeling emotionally drained and that they often burst into tears when they were alone.

" But I struggle emotionally in my workplace too much, from my colleagues constant talks about kids and questioning my pregnancy delay".

(27 yrs. 5 years of infertility)

The emotional pressure was so tremendous for one woman that it led her to think of seeking support from a psychologist if she failed to cope with the social pressure.

"Sometimes when I think about it...I say if I stayed like this for longer and I continue having this pressure on me I might decide to go look for a psychologist for help"

(28 yrs. 3 years of infertility)

5.7.2.4 Feeling Inferior compared to other fertile women

Many women noted that people around them made them feel inferior to other fertile women, which in turn negatively affects their self-esteem. Many of the participants described this in a form of being labelled as disabled women, infertile

or women with a defect in their femininity, due to not carrying a pregnancy. Several women reported being pitied by others:

> *"Oh Allah (God) it happens spontaneously when they start talking about it, I start to get really annoyed because I don't like this feeling to be in an inferior position, they think she is worthless as she cannot give birth to children, people look at us from a superior position...even when I meet friends or family, I can feel that they don't appreciate me because I don't have any children and look at me sympathetically and make me feel uncomfortable".*
>
> **(30 yrs. 4 years of infertility)**

Another woman said:

> *"They think that if I have a pregnancy delay, it means that I am having a disability"*
>
> **(32 yrs. 6 years of infertility)**

Women also described how infertile women were viewed as evil, where women avoided telling them about their pregnancy and tried to avoid letting them hold their children, as they might envy them and cause something bad to happen to them or to their children:

> *"People might be afraid of us that we might be over sensitive and evil towards pregnant women or those with kids...so they stop telling us things such as hiding their pregnancy around us or if a woman is carrying her baby, she will try to avoid us or avoid allowing us carry her baby as they are afraid of our envy and harm"*

(33 yrs. 3 years of infertility)

5.7.2.5 Feeling guilty about being unable to grant their husbands a child

The majority of participants indicated their disappointment at not being able to fulfil their husband's wish of having children, especially when they were the reason behind infertility (due to their PCOS). Many expressed their husband's desire and care towards other children and how they felt guilty about being unable to grant them one.

> *"Now every time I have an appointment I don't tell him about it to avoid him accompanying me and not hear what they say in the clinic because it makes me feel more guilty about all this"*
>
> **(30 yrs. 4 years of infertility)**

5.7.3 Fears and concerns about infertility and its consequences

Despite the fact that many of the participants had a positive attitude in perceiving their pregnancy delay through holding on hope and having strong faith in God, they were open to share their fears and concerns from experiencing infertility. These concerns are further discussed below.

5.7.3.1 Not to experience motherhood

The desire to carry a successful pregnancy and experience motherhood was inherent among the sample. Many participants although were hopeful to conceive, expressed their concerns around never experiencing motherhood. Having such thoughts are terrifying to them as being mothers was an instinctive desire among

women in general. This was discussed by a 31 years old participant who had experienced pregnancy delay for 10 years:

> *"The idea of having children is now becoming my life after waiting for so long and I wish I can have a child and I hear someone calling me "Mama"...I'm afraid I'll die before I get to experience this"*

5.7.3.2 Concerns around the chances of conceiving reducing with increasing age

About a handful of women expressed concerns about having difficulties conceiving with increasing age. These concerns were more common among those who had experienced infertility lasting 4 years and more. For example, one lady expressed that initially she and her husband were not keen to seek and follow fertility treatment until 4 years had passed, and thus they realized their chances of conceiving were decreasing with time:

> *"4 years have passed until we started to understand and accept the whole issue that we are getting old and we said it is enough and we should take this seriously"*
>
> **(34 yrs. 4 years of infertility)**

Several women were considering the longer-term implications of not bearing children, such as not having children to look after them during old age, which is typical of Omani culture. A participant gave an example of her aunt who is a widow and who had grown old and was without children;

> *"Honestly, I think about my status when I am older...for example; my aunt is very old and a widow without children to look after her and I see her moving from house to house because she needs someone to take care of her which is*

a terrible situation...and sometimes I say that I might be like her in the future but if I have a son, he will take care of me...that is why I am trying to conceive"

(35 yrs. 10 years of infertility)

5.7.3.3 The impact of Infertility on couples' relations

Despite many participants reporting feeling strongly supported by their husbands throughout their infertility journey (discussed in more detail below: see section coping mechanism under theme living with infertility), half of them expressed their worries about how difficulties and delays in conceiving could affect and threaten their marital status. The main concerns among these women related to thoughts about their husbands remarrying in order to have children; Islam permits that men can marry up to four wives.

"Yes for sure I'm worried that my husband might marry another woman, the fear is always there"

(24 yrs. 4 years of infertility)

Others were worried about getting divorced or for their husbands to no longer feel attached and affectionate towards them. Factors contributing to such tension were mentioned, such as men being subjected to social pressures from their families, particularly to remarry if their wives were deemed to be taking too long to conceive.

"My father-in-law's personality is very influential and can change his son's mind by one word, and this scares me a lot that he can change my husbands' opinion easily to remarry as he refuses this idea for now...so I don't know how the future will be"

(24 yrs. 4 years of infertility)

A few of the interviewed women revealed how the issue of pregnancy delay has already affected the stability of their marital life and this was more apparent among couples with pregnancy delay periods of 4 years and more. These tensions partially arose from the social pressure especially from in laws who pressurise their son to look for a new bride. A participant with infertility for 4 years discussed this:

"Yes it affected us so much...I can feel that we became less connected with each other because he is out of the house most of the day and there is nothing that connects him to me, oh Allah (God) when he gets bored or exposed to pressure from his family who keep on bringing the subject of a new wife constantly so he would say a word to me that I don't like and I will get back to him with another word and then a fight will easily start...it has become our every day's life"

Another woman with a pregnancy delay of 7 years noted:

"You can feel that there are things that are getting started and you don't know how they got started. Then, you sit down and think how he was before,

he used to love me more and give me attention and etc., why he has changed?...and he goes to another person who has children you feel like...I don't know...he compares us to them and you can feel that the delay of pregnancy between the couple is the main source of problems between them".

5.8 Theme 2: Cultural aspects around infertility

5.8.1 Beliefs around child bearing

5.8.1.1 Infertility is always attributed to the woman

Half of the participants mentioned that they felt blamed for the pregnancy delay (Appendix G2). Women expressed how culturally pregnancy delay is always considered a woman's fault. Society does not accept that men may be the reason behind problems in conceiving.

"Yes, it is me who is being blamed...despite that I am much, much younger than my husband but he refuses to do any investigations to check .The community considers it as a very negative thing...if you don't get pregnant within a year they say that she is infertile and will not ever have children and our son will remain without children. They always say: you are the one who is causing this problem even before I started the investigations"

(19 yrs. 1 year of infertility)

Moreover, it is shameful to refer a pregnancy delay to men. Therefore, Omani societal views and culture will always push men to remarry once there is a

pregnancy delay from their first marriage to prove their fertility. This was apparent from an interview with a 31 year old participant:

> *"My mother in law doesn't know for sure whether the problem is from me or from my husband and focuses only on me and asks me many questions from time to time and blames me for the pregnancy delay, the husband is out of it and all the pressure is on the woman, they think that men are always fine and not suffering from any deficiencies and she is the one who always suffer from all the problems...for example one of my husband's relatives had the same issue and the woman was the one seeking treatment all the time assuming the husband is fine until he decided to marry another woman, but his new wife could not conceive as well until he was advised to visit a clinic for male reproductive disorders and found the fault to be from him..so the woman has been unfairly treated as always".*
>
> **(31 yrs. 10 years of infertility)**

Another reason to put the blame on women is the societal belief that women inherit their subfertility from their families. A proportion of the participants discussed how their in laws suggested that the problem must run in women's families. Therefore, some women went on to state that family members would start to question relatives' histories to find out more about the ones with the same issue of infertility to try and prove that they will end up being infertile like them.

> *"Sometimes they talk about my family problems with pregnancy delay to conclude that it is a genetic thing in my family and say that my brother*

waited for 3 years to have kids and I might need 6 years...they have a very weird belief in their minds that if my brother or sister who is older than me experienced a pregnancy delay, this means that I will need double that period of time to conceive if at all"

(19 yrs. 1 year of infertility)

5.8.1.2 Infertility is caused by envy and an evil eye

Many participants were told by family members and friends about non-medical causes that could explain their infertility. Participants admitted that there are common societal beliefs around the reasons behind infertility among couples. People believe that couples might be envied by others or that an evil eye causing a form of curse from people around them that have stopped pregnancy from happening. Therefore, couples stated that they are often pressurised to attend religious healers called "sheikhs" who use herbs or recite verses from the holy Quran to revert the act of devil. A 25 years old participant with 2 years of infertility mentioned the pressure to visit these "sheikhs"

" People told me "it might be an envy" or "go and seek a solution" or "treat yourself by Quran"...and they have started to drift away from the reality, but we don't believe in their ideas we stick to our values and beliefs, they told me stories of family members who had a delay in pregnancy but got pregnant later and delivered and they used to be treated by Quran and treated successfully from the envy, so, many people advised me to go and get treated by Quran as well, but it is not the case for me because I have a

medical problem which is PCOS that causes the delay ,so people are different and not all are the same"

(25 yrs. 2 years of infertility)

More than several of the participants were encouraged by their family members and friends to seek traditional treatment instead of a medical route. Although many of the participants did not believe in these traditional treatments, they did end up visiting them due to the social pressures they faced and due to some of the successful stories they had heard of.

"My sister told me about a woman who does rubbing for women who has the same as my problem who successfully got treated and carried a pregnancy, but I am not convinced about it...I said that medicine is much stronger and safer, and I was scared about the herbs they use and that it might affect me negatively... I don't trust them"

(31 yrs. 10 years of infertility)

Many participants explained these healers, that were women, practised abdominal rubbing techniques to shift the position of the uterus, which they believe is inverted, and thus causes pregnancy delay. Others would use some herbal medications to be ingested or to be inserted vaginally to help them get pregnant.

"One of my colleagues told me to try the rubbing and she convinced me. We went together to a healer she was a lady who gave us herbal drinks and honey and used abdominal rubbing techniques to remove the dirt from the uterus and reposition it and then she inserted certain herbs into the uterus, my friend benefitted but I didn't."

(34 yrs. 4 years of infertility)

5.9 Theme 3: Living with infertility

Further discussion with participants on their experiences of living with infertility revealed the different forms of social pressure they encounter on a daily basis. Discussions revealed that many participants had adopted different techniques to help them cope with social pressures from both family and friends (Appendix G3).

5.9.1 Social pressure and expectations

The majority of women complained of tremendous amounts of social pressure exerted on them from the society within which they are living in, because they suffer from pregnancy delay. Women reported that the community and their culture expects pregnancy immediately after marriage. Women reported other women were direct in asking newly married women about whether they are pregnant, even if it was only few months since marriage. It was reported that not being pregnant within a year of marriage was enough for the woman to be labelled infertile.

A participant explained how her husband's family expected grandchildren soon after marriage, especially from their eldest son in order to carry the family's name:

> *"What affected me the most is my husbands' family who are waiting for a baby so bad because my husband is the eldest son and they want a grandson to carry their name. They expected pregnancy right after marriage but when that did not happen all the pressure started"*
>
> **(25 yrs. 2 years of infertility)**

In response to these cultural expectations, women were constantly pressurised and the different forms of these harassments are discussed below:

5.9.1.1 Comparisons with other couples

Half of the women mentioned being constantly compared to fertile women, by their in laws. Women mentioned that their husband's family often made comparisons to other couples who had either got married around the same time or after them who had conceived or had children already:

> *"I am living with my parents in law and his brother married after us and got children and they are constantly comparing us to them. One day it was Eid (festival)and we were all sitting in a big hall, full of women and girls and a lady approached me and said to me "how long will you be waiting for to have children?! All who have got married before and after you have got children by now" and it made me so embarrassed"*
>
> **(30 yrs. 3 years of infertility)**

5.9.1.2 Frequent questioning

Another form of social pressure discussed by women is that they were frequently asked about the delay. All of the participants mentioned people being 'nosy' and that in some cases they were repeatedly being asked whether they were pregnant yet, each time they encountered certain individuals. Moreover, participants reported that some people even asked explicitly whether they had faced any issues with pregnancy and whether they started following up and receiving any treatment for it; this was something that annoyed participants immensely;

“One of my husbands' family members used to ask me each month during my first year of marriage about pregnancy and said “I will continue asking you until you get pregnant””

(25 yrs. 2years of infertility)

“Our family members tend to ask a lot about it...like "do you go to treatment?!", "why you are not pregnant yet?!"..."who is causing this problem you or him?!"”

(32 yrs. 12 years of infertility)

5.9.1.3 Judgemental comments

In addition to being frequently questioned about their pregnancy delay, women in the community have exposed women with pregnancy delay to embarrassing situations (Appendix G3), which made them feel inferior to others. A 32 years old woman with a 6 years period of pregnancy delay describes this:

“Once I was leaving my neighbour’s house when I passed by a group of my neighbours who commented loudly “why are you not pregnant yet? Do you think you are still young?!”

(32 yrs. 6 years of infertility)

Another one mentioned

“My husbands' grandmother once said in front of everyone when I was visiting my sister in law who had just delivered that I must be stopping my husband from practising sexual intercourse with me and as a result, there is

no pregnancy till now...which made me feel so embarrassed in front of everyone and both me and my husband were very disturbed as a result"

(24 yrs. 4 years of infertility)

Moreover, some comments made some women feel inferior and less feminine compared to fertile women. A 30 years old lady with 4 years of pregnancy delay mentioned how other women did not trust her to baby sit their children as she lacks the experience to do so:

"When I met my brothers and tried to play and take care of their children, they would tell me that I don't know how to treat children as I don't have any experience with kids and they would keep telling me to do this and that"

A similar situation was narrated by another participant:

"Women told me that I don't know anything about pregnancy and I cannot participate in their discussions about pregnancy and delivery...ok I might have not tried it but I know...they will stop me as I haven't been through it so I will stop talking and I keep my mouth shut"

(28 yrs. 3 years of infertility)

5.9.2 Coping mechanisms

Under all the psychological and social pressures exerted on these women by the community, different coping mechanisms were being used (Appendix G3).

5.9.2.1 Husband's support

Since most of the pressures felt by women stemmed from their in laws, many stated that their husbands were supporting them, particularly to help them bear the stress induced by their families:

> *"When I get bad comments from my in laws, my husband follows me usually and asks me why are you crying? And he tells me that the most important thing that we are satisfied and in agreement and asks me not to care about anything else"*
>
> **(19 yrs. 1 year of infertility)**

Similarly another participant said:

> *" when I get upset and discuss with him the idea of him to get remarried, my husband rejects it and removes it from my head and tells me "why do you keep thinking about it?! Don't let anything affect our relationship"; and he told me, "the most important thing is that we are understanding of each other"*
>
> **(27 yrs. 5 years of infertility)**

5.9.2.2 Self-distraction

Self-distraction was an additional coping mechanism interpreted from the interviews with the women. Women mentioned that they took up different activities, such as household activities, meeting up with family and friends, going out for a walk or watching television throughout the day to distract themselves

from the feelings of loneliness described above (See section on the impact of infertility on emotions under theme: Self-perception of infertility p 144).

> *"Initially I had the idea of having children to occupy my time... but when it didn't happen for so long I had to do something else...I was so bored so I used to keep on changing the decoration of the room I shared with my husband in my in laws and keep cleaning it each time but staying in that house for 10 years made me bored of changing the decoration of my single room every day, but I tried not to stay without doing anything"*
>
> **(31 yrs. 10 years of infertility)**

These activities provided comfort and were a good way to avoid negative thoughts about their infertility status. It was also a good way to change their mood. The women described how their husbands also engaged in self-distraction strategies too, such as taking up afternoon jobs or starting their own small business to keep them busy after daytime-work hours (Appendix G3).

Others shared the activities they were occupied with:

> *"I have started to study some courses, a bit from here and there and tried to get out of constant thinking. I mean I was thinking too much alone about my pregnancy delay"*
>
> **(22 yrs. 7 years of infertility)**

5.9.2.2.1 Social adjustment

Some women reported trying to make some social adjustments to help them avoid being exposed to people's negative comments. These adjustments were mainly in

two forms; the first was moving out of their in laws' house and into their own home. Many of these individuals found it easier to adjust to their life being away from their in laws' constant questions and comments. They were also more stable emotionally and had better control over their relationship with their husbands.

> *"Honestly I want to tell you for the first time that I wanted to move away from them and it's my first time to say this to anyone but I thought I will be able to convince my husband to move away from his family because of the bleeding issue I had, they have been a source of stress and pressure for me...so I had to move and live with my husband peacefully"*
>
> **(24 yrs. 4 years of infertility)**

Secondly, other individuals mentioned that they avoided attending social gatherings that were likely to be attended by women and children, such as weddings, birthday celebrations and visiting newborns. These sorts of events were associated with a greater likelihood of being questioned or bullied about not having children:

> *"I am now avoiding the women gatherings like Eid or birthdays or when I know that there are some pregnant women who are attending because they will look down on me due to this problem as I have been married before most of them and still with no kids"*
>
> **(30 yrs. 3 years of infertility)**

Some women mentioned that their husbands had also started to avoid social gatherings too:

"One day I noticed that my husband started to avoid going to the masjid (mosque) for prayers and every time he says a different excuse; I'm late, my leg hurts…etc. until I confronted him one day and he said every time I go to the masjid they say we will help you find another woman to marry and get you children and he didn't want to tell me because he didn't want to make me upset. Now he has changed the masjid from the one he used to attend"

(30 yrs. 3 years of infertility)

5.9.2.3 Adopting a healthy lifestyle

Among the life adjustments adopted by these women was adapting to a healthier lifestyle. Half of the participants committed to eating healthily and engaging in physical activity. Many of the women had been advised to lose weight by their HCPs, because it would help to increase their chances to conceive, especially because women with PCOS most often are overweight. Women either attended specialist nutrition centres for dietary advice or tried to eat healthier by cutting down on carbohydrates, fatty and sugary foods. Women also either subscribed to a fitness centre or were committed to exercise, through walking routinely in the neighbourhood. Physical activity apart from being beneficial for their fertility treatment seemed to help participants manage their free time and lift them spiritually. A participant who convinced her husband to join her in her quest for healthier lifestyle said:

"I convinced my husband and now we have changed our food style, we increased the fluid intake and salads and decreased the fatty food by

replacing it with fruits and we have started to have early dinner before the evening and we don't eat any fatty food at night...we both go to the gym and I am enjoying my time a lot being physically active, I mentally feel happy training and I will continue doing this even after I get pregnant"

(25 yrs. 2 years of infertility)

5.9.2.4 Coping gets easier the longer the infertility

Women stated that coping with infertility gets easier with time. Women get stronger emotionally and less sensitive to the social pressure about their infertility the longer it takes with pregnancy delay. A 34 years old participant with 4 years of pregnancy delay shares her experience:

"But all I can say is Alhamdullilah (thank God) I got used to it now and I get less affected by people words"

Another one with 10 years of infertility said:

"Now I am accepting all these circumstances more and tolerating even when someone talks to me about it and talk for a while I respond that I can't do anything since it is Allah's (God's) decision. I'm over it by now"

(31 yrs. 10 years of infertility)

5.10 Theme 4: Adoption in the Omani community

Further discussions with the participants helped understand their opinion about the notion of adoption given the context of living in Oman. Most participants thought

that adoption might be an option for them in the future, if their endeavours to conceive failed. However, a notable group of women rejected the idea (Appendix G4). Many participants pointed out during the discussion that adoption is uncommon and is not a norm among Omani people. While a couple women reported never knowing/hearing about the possibility of adopting children and raising them as their own. Others never heard of any of their friends or relatives who had adopted before.

> *"This idea didn't come across my mind before, we didn't talk about it or discuss this issue before. It didn't happen to talk about it previously...All I know that you can only sponsor an orphan by sending money on a monthly basis to some bank accounts"*
>
> **(31 yrs. 10 years of infertility)**

Analysis found that women shared some of the common beliefs among the community, surrounding adoption, which resulted in several sub-themes.

5.10.1 Community's view on adoption

Results suggested that the community in general held negative views towards adoption and this was mainly attributed to reasons, such as adoption being forbidden in Islam, rejection of whom these children are and taking up this step is considered as confirmation of a couple's sterility, these are further discussed below:

5.10.1.1 Adoption is forbidden in Islam

A number of participants believed that Islam forbids adoption and therefore anyone who does so is considered to be disobeying Islamic rules and regulations, and therefore they were sinful as a result. Participants mentioned that adopted children are considered strangers to the opposite gender of their adoptive parents especially when they mature, as they are not their biological offspring. As a result, participants discussed that adopted girls will have to cover up in the presence of her adoptive father when she becomes a grown up woman. She will not be allowed to have close physical contact with her adoptive father such as, shake hands, hug or kiss him as normal daughters might do with their fathers. Participants reported that in Islam, adopted girls could get married to their adoptive father, as they are considered strangers to them.

> *"If the adopted kid is a girl, people will say how your husband will treat her in the future and if it is a boy they will ask you how you would treat him in the future??....so after raising him or her, I should take them out of the family which is not acceptable...I mean they might say it is more acceptable to embrace children financially where they are more independent, they will not be living with them in the same house but they can visit them frequently...so I don't think that I can raise a baby boy and when he gets older I would be told by Islamic scholars that I can't treat him like before and he is a stranger to me"*
>
> **(35 yrs. 10 years of infertility)**

5.10.1.2 Rejection for whom these children are

The second reason for the community's negative views about adoption related to where these children originated. Most of these children are believed to be foundlings that have originated from sinful relationships outside the context of marriage. They are considered to have been abandoned right after delivery due to the shame associated with them. Participants explained how these children most often are being thrown at the mosque doors or at hospital doorsteps for people to find them and take them to orphanages. Participants admitted that it is difficult to accept children of unknown parents, as they believe they will be hugely discriminated and treated unfavourably in the community:

> *"My uncle works as a police officer and one day he brought a little baby girl, whose parents died in a car accident and she was abandoned by her extended family and gave this baby to his wife because she had experienced a medical disorder that prevented her from having more children...so people didn't believe the story and said she must be a foundling child...and when she got married, a huge party was done for her and people said "why do you spend all this money on a foundling child?! She doesn't deserve all this, we don't even know where did she come from, we don't even know her family", people still don't accept her despite all these years"*
>
> **(31 yrs. 10 years of infertility)**

Participants mentioned that it was more common and acceptable to raise an orphaned child from family members instead, as these children are considered

family members and it is their responsibility to look after them following the loss of their parents.

> *"In some cases when parents die and their children are left alone they will be raised by the family relatives which is ok and normal because they are considered from the family and everyone should be responsible for raising them and it happened before several times ... I believe there are many negative ideas such as adopted kids will not be able to marry from our family because adoption affects the family's lineage and so on and therefore people worry about the future of adopted kids"*
>
> **(22 yrs. 7 years of infertility)**

5.10.1.3 Confirmation of a couple's sterility

Some participants indicated that adoption served to confirm a couple's sterility to the community. Adoption is seen as the last resort for couples that cannot conceive as it is considered a huge step and no one is expected to have the courage to do it in Omani society, unless they have been diagnosed with sterility or if couples are too old to have children of their own. Therefore, other couples would prefer to get divorced or remarry than adopt children for the sake of experiencing parenthood (defined as bearing own offspring).

> "If the couple are too old and waited for a very long time to conceive it's ok to embrace a child, but if it was for a couple who are still trying and young it's not an option to adopt or embrace a child, people might say that there

must be something wrong with them and they must have been told they are sterile"

(22 yrs. 2 years of infertility)

5.10.2 Women's views on adoption

More than half of the women were seemingly open to the idea of adopting, but they still expressed concerns in taking this step. These included having limits in raising adopted children, feeling that they would lack real compassion towards them, and feeling that they would be responsible for exposing them to society's discrimination; these sub-themes are discussed below (Appendix G4).

5.10.2.1 Limitations in raising adopted children

A handful of participants thought it would be a challenge to raise adopted children. Concerns around how to discipline them were raised, where many thought it would not be appropriate to scold them or get angry at them, or maybe spank them if they did anything wrong as parents might normally do with their own children. They also discussed how doing this would be considered sinful.

"I can say that it is a big responsibility and not an easy one…I mean it is not like your own child…when it is your child you can punish if he does anything wrong, everyone will think this is your way to raise kids but when he is adopted it can be seen as an abuse and not an upbringing"

(25 yrs. 2 years of infertility)

They also discussed how doing this would be considered sinful.

"Some of them told me to go and adopt a child but when this child is not from you, you can't truly feel that he is your child, is this right?! Because when you adopt a child, you can't feel that he is your child that has your soul…the adoption is different; for example, if he has done something wrong and you punished or hit him you will be considered as you have done a sin"

(30 yrs. 4 years of infertility)

5.10.2.2 Lack of real compassion towards adopted children

Women expressed an additional concern around feeling a lack of real love, compassion and emotion towards adopted children. Not being their biological mothers was an issue of concern too. Many felt that they would not be able to give adopted children the love and care they needed, as they would perhaps give more naturally to their own biological children.

"One day I thought about it before but then I was afraid not to accept them after embracing them and treat them without feelings or compassion"

(33 yrs. 3 years of infertility)

"I can feel that not too many are accepting this idea ...I mean when it is not your real child...you will not be attached to him like the attachment with your real child"

(22 yrs. 2 years of infertility)

An additional source of concern was that children in return would lose the love towards their adoptive parents after learning that they were adopted:

> *"whatever it is but there is no any real relationship between the parents and the child even if you raise him...I know a woman in my neighbourhood who have been raised by a couple but later I didn't feel that she was compassionate to her adoptive mother who raised her...I didn't feel that it was a real relationship...this is my opinion"*
>
> **(35 yrs. 10 years of infertility)**

5.10.2.3 Exposing adopted children to unfavourable social situations

Women were concerned about adopted children being mistreated by others, as a result of being adopted. More than a handful of participants shared their worry about feeling responsible for any suffering these children may face e.g. rejection by other family members. Furthermore, they revealed how adopted children might themselves reject their adoptive parents in the future thinking they were adopted out of sympathy.

> *"My only concern is that when they grow up and understand that we are not their true parents...at that moment they will start thinking that we were sympathetic and brought them here to live with us etc...and when they start to be independent they will say that we raised them and spent money on them despite that they don't know us and to be honest, I don't like to be the reason for that mercy feeling that they might feel later on"*
>
> **(19 yrs. 1 year of infertility)**

"For me, why should I bring a child and let people treat him unfairly and make him feel that he is embraced and looks pathetic to others, because he is not living with his real parents after all I will be the one responsible for him to have all these feelings and misery, as it wasn't his choice"

(28 yrs. 3 years of infertility)

Another participant noted that even if adopted children were accepted by the community initially, no one would accept them for marriage as they are of unknown origin, and family lineage is considered to be very important in marriage, in Omani society:

"It is going to be easier when they are children but when they are older it is going to have many problems …. for instance If you raise a girl who was a foundling child, and one of your family members falls in love with her and want to marry her it is going to be a big problem....in our culture people will not accept them as part of their families"

(30 yrs. 4 years of infertility)

5.11 Experiences with healthcare offered in fertility clinics

5.12 Theme 5: Access to healthcare services

Discussion with participants explored their experiences with the healthcare services offered in fertility clinics. This included initial access and their expectations, experience of the communication with fertility HCPs, the extent to which they received emotional support and their experience with the other fertility services

offered (Appendix G5). Core themes and sub-themes related to participants' experiences with healthcare service are listed in Table (5.22).

5.12.1 Shift from private to government healthcare services

Results showed many of the participants preferred to start their fertility medical follow-ups and treatment in private hospitals and clinics (Appendix G5). Reasons for this were attributed to the ease in which they could access these clinics, and thus avoiding the long wait times to get an appointment in government clinics. Second, participants perceived that private clinics had better diagnostic devices and treatment options compared to government clinics. Thirdly, private hospitals were viewed as being more private for couples compared to the often over-crowded government clinics. Moreover, private clinics were more amenable for husbands to attend follow ups compared to government clinics, where treating women was prioritised and men were not normally allowed in the fertility clinics, or that they are called only if needed. In addition, there were no appropriate areas allocated for men to give semen samples for analysis in government clinics, which makes it difficult for the sample to remain viable if they were to travel from cities far away from the hospital.

> *"I was happy because I planned beforehand that I will attend the clinic here for treatment and what made me happy the most that it is a governmental centre so we don't have to pay, and the good about private clinics that I get appointment right away and its very private especially for husbands and we*

thought the doctors and treatments are better there but no it's the same treatment options here in government and very good doctors too"

(34 yrs. 4 years of infertility)

However, some individuals reported dissatisfaction with private clinics, but these tended to be related to the regional hospitals and those that were abroad:

"I have travelled to Pakistan and didn't find any successful treatment.... she gave me a medicine but didn't treat my problem…she said that I have PCOS and gave me a medicine to be used for a month and after that nothing happened. I went everywhere I also attended some private clinics in Nizwah, Ibri (cities in Oman), Alain (a city in United Arab of Emirates) with no success"

(28 yrs. 4 years of infertility)

Despite expressing preferences about private clinics, these couples moved to government clinics eventually. The main reason for the move was that private clinics were expensive. Participants described that the longer the pregnancy delay, the more extensive and repetitive the investigations get and therefore bills accumulate, where most people will no longer be able to afford to stay in the private setting

"Before I thought that private care centres are better than government hospitals ...so I have spent lots and lots of money in the clinics for nothing and they were only giving me injections which made me so tired, so I decided not to go there again and my husband spent too much money as he is not an

employee...so I told him that we have had enough spending money for nothing we can get better doctors and treatment for free in government hospitals"

(24 yrs. 4 years of infertility)

Second, participants mentioned that they hear about the comparable diagnostic and treatment services available in government hospitals that are free to access.

"I was afraid that it was the first time for me to visit a government clinic but everything was fantastic the treatment is very advanced and similar to that in private and for free! I was surprised"

(28 yrs. 3 years of infertility)

Thirdly, many participants seek expert opinions which they believe is only available in private clinics, and by attending these clinics they find that the same doctors in private clinics also run clinics in government centres so they move over.

"I have been advised to come here for treatment due to the presence of consultants who are qualified, although I waited for long time to get my appointment but it's worth it as these doctors are also have their private clinics and people go there and pay money just to get treated by them"

(31 yrs. 10 years of infertility)

Finally, many were encouraged to follow up in the tertiary government clinics after hearing of successful stories from family and friends who had received treatment in these settings.

"They have told me about this hospital and told me that it is great and I might find good results here as many women got pregnant here after a long time of pregnancy delay, so I said, I will go and make an appointment hoping that I will have the results that I am looking for."

(32 yrs. 12 years of infertility)

5.12.1.1 High expectations accessing tertiary governmental fertility clinics

Further discussions with women revealed the high expectations they had when accessing government fertility clinics following receiving care from private clinics. Many hoped to find a better treatment plan and wanted to take advantage of the highly qualified physicians' opinions about their medical condition. Most participants were pleased to be among the ones who had the opportunity to be treated in the country's highly specialized fertility clinics. Normally referrals to these clinics would be filtered based on meeting the criteria for infertility to be eligible for treatment. Typically, it takes about 3-4 months to be given a first appointment, due to the high numbers of patients seeking treatment in these clinics.

"I was happy and stressful at the same time because I knew at that moment that I will receive proper treatment from the hospital… so this made me feel very optimistic to find a solution for my problem"

(31 yrs. 10 years of infertility)

Another participant was pleased to be receiving a high fertility technique like IUI;

"In X hospital(a regional hospital), I mean I can't say that it is very basic, thank God there is some development but still, there are no specialization there, even the IUI is not available there...if the condition becomes complicated they will make a referral to another hospital. So, thank God, I have got the opportunity to be treated here directly. I was lucky and I have hope this time"

(31 yrs. 10 years of infertility)

Despite most participants feeling hopeful and optimistic about getting positive results, a couple of women expressed concerns about being diagnosed with a more complicated condition when attending initially, that this would be different to the previously diagnosed PCOS condition in the clinics they have visited before:

"I was afraid of the results of my investigations to be different than other hospitals but alhamdullilah (thank God) they were the same and nothing new...it is the problem of PCOS"

(32 yrs. 12 years of infertility)

5.13 Theme 6: Communication with HCPs

Communication with HCPs is vital for patient's satisfaction with the received care and their acceptance of the extensive fertility treatment process they normally go through (Appendix G6). Participants shared their experiences of dealing with HCPs in the clinics where they were currently receiving treatment (at the time of the interview). Certain shortcomings were mentioned around lack of information on medical condition and procedures, language barrier, the opposite gender of the

HCP as a barrier, limited role of nurses and the short consultation time. These are further discussed in turn below.

5.13.1 Lack of information about their medical condition and clinical procedures

Although many participants were generally satisfied with the level of expertise and services available in these two tertiary fertility centres compared to the private clinics they have visited before, they also shared some of gaps in communication especially around their diagnosis of PCOS and infertility and the nature of the medical procedures needed in management, and thus suggested room for improvements (Appendix G6).

Participants felt there was a lack of information given by the physicians about their condition and the reason for pregnancy delay, treatment plan and the nature of the procedures that they would be receiving. Participants mentioned feeling confused about the nature of PCOS and how to overcome it and were not sure if it was the reason behind their pregnancy delay.

> *"It was all about asking me some questions and I will answer but they didn't show any further response...they only gave me the plan and they will start telling me to come and go, come and go... they didn't explain the reasons behind the pregnancy delay nor they gave you any models to show me...or anything else and about the laboratory tests, no one explained the types of tests that I am going to do. They will just say go to the laboratory to collect some blood samples and that is it"*

(31 yrs. 10 years of infertility)

Due to the lack of information received from physicians on the nature of the medical procedures, women reported searching the Internet or asking family and friends who had undergone similar procedures before. Unfortunately, in some cases this led to misinformation.

"No one explained it to me...and I asked my family relative who has done it here about the procedure and she explained it to me it's a probe that gets inserted through belly button... and when I attended that day to do the fallopian tubes radiological examination, I had my period, then she told me they can't do it that day because there might be a chance for conception to happen and they explained that procedure will be through the vagina not belly button!! Which was very different from what my cousin told me!"

(31 yrs. 10 years of infertility)

This lack of information was compounded by the lack of educational and illustrative materials for patients;

"It is the physician who tells me about it and explains to me orally which is difficult to understand at times, and she doesn't give me any leaflet for further information"

(27 yrs. 4 years of infertility)

5.13.2 Language barrier

There was a language barrier that hindered communication between some of these women and physicians. This was typical for women who were dealing with a non-Arabic speaking physicians, which limited the exchange of information between them.

> *"I was going to talk to the physician about many things but I felt she will not understand me well because she is a non-Arabic speaker and my English is not that good, so I didn't speak to her and she was in a hurry and didn't tell me about the treatment I use....she only wrote my medications on the computer and told me to take them again"*
>
> **(31 yrs. 10 years of infertility)**

Although Omani nurses were asked to attend the consultation for translation purposes, participants were not always comfortable to have the nurses around plus they were not always available and free to translate.

> *"Sometimes I ask for a nurse to translate what the physician is saying...but this happens when they are available but sometimes they are busy"*
>
> **(35 yrs. 10 years of infertility)**

5.13.3 Gender barrier

Having a male physician in the clinic was considered an additional communication barrier for the participants who had encountered them. Although the presence of a male physician is not common in the obstetrics and gynaecology clinics in Oman, a

number of the interviewed participants encountered male physicians during their follow up visits. These women admitted they felt uncomfortable when having to share medical information related to their fertility problem with the male physician.

> *"I felt a little of discomfort...I wasn't comfortable when I attended the male physician unlike the female physicians...because I was alone and my husband was in his job...I couldn't argue with him as I did before. I was really embarrassed when he asked me about the menstrual period and he asked me is it coming regularly... and I answered no it is not...why did he ask me if that answer was already written there in the report, I really wasn't comfortable and I felt awkward"*
>
> **(22 yrs. 4 years of infertility)**

One of the participants expressed she was less bothered by this, but further discussion revealed that she still found it restricting to deal with a male physician, when it comes to gynaecology issues and that these restrictions were exacerbated when the male physician was non–Arabic speaking too;

> *"There are some barriers always if the doctor is a male and especially if he is also English speaking, but as you know that sometimes necessities will override the prohibitions"*
>
> **(31 yrs. 10 years of infertility)**

5.13.4 Nurses and their role

A number of women expressed being more comfortable communicating with nurses in general compared to doctors, in particular the Omani ones versus the

expatriates (Appendix G6), because they were more understanding of the cultural and social pressures felt by women. Nurses were perceived as being more accessible and available as they spent more time with them in the clinic and they saw them more frequently during their medical tests, compared to the time they spent with doctors. Therefore, nurses were thought to be easier to build a rapport with.

> *"I can say that even the Indian nurses are good but I prefer the Omani nurses because I can feel that they do care about you more and about your problem...the non-Omani nurses are making small mistakes a big issue for example when you are late, but the Omani nurses tend to facilitate our visits even when you come late they will try to help you and find a way to deal with us as they are from our culture and can feel for us more"*
>
> **(30 yrs. 4 years of infertility)**

In contrast, a few participants mentioned the limited role nurses play in the clinic. Doctors were perceived as having more authority in the clinic, particularly in terms of giving information to patients on medical tests and procedures, and to convey test results to them. Staff nurses' roles were viewed as being limited to guiding patients through these tests, typically because they were not authorized to explain procedures nor share the test results with the patients.

> *"The physician is the one who gave me the appointment and call me on the phone...the physician is the one who does everything"*
>
> **(27 yrs. 5 years of infertility)**

5.13.5 Short consultation time

A number of participants were annoyed by the short time allocated for consultations. This was mainly due to the overcrowding in the fertility clinics by the high numbers of patients coming for follow-ups. The high pressure on the treating doctors limited the time available to discuss participants' conditions comprehensively and to build a rapport with them.

A participant was upset that after waiting for a long time for her appointment in the waiting area, she was seen very quickly by the physician who finished the consultation in a very short time not allowing her to discuss her concerns;

> *"The communication is very important part of the treatment, if both the patient and the physician are understanding, the treatment results will be better and easier and the patient will be more accepting of the treatment...I was waiting for my turn for so long and I had a lot in my mind to discuss that day especially I waited for 2 months for this follow up appointment, but when she called me in she started to call me using another name!!, so I told her my name is X so when she realized this, she spent long time looking for my reports... I think it is kind of neglect, as a result she gave me only 10 minutes and was staring at her computer all the time, I couldn't discuss anything with her*"
>
> **(31 yrs. 10 years of infertility)**

5.14 Theme 7: The provision of emotional support

The extent to which emotional support is offered in fertility clinics was also discussed during the interviews. Most participants expressed the lack of emotional support from HCPs during the consultation process. Different reasons were proposed by participants, such as the limited consultation time, HCPs avoid embarrassing patients, the focus is to treat the organic cause and it is not being a standard of care (Appendix G7).

5.14.1 Lack of professional emotional support

Many participants were happy with HCPs' overall attitude and friendlessness in communication. Many participants also reported that HCPs often gave them words of support and hope, but in general they did not check on their emotions and how they were coping with their infertility for the below discussed reason.

5.14.1.1 Limited consultation time

More than a handful of participants referred to the lack of time during the consultation due to the large numbers of patients to be seen and the small number of fertility HCPs as barriers to discussing emotional wellbeing.

> *"I think because they are very busy and has a load of patients...so there is no time to discuss anything else, I think they might feel that it is not important to ask about the feelings and it doesn't cross their mind"*
>
> **(28 yrs. 3 years of infertility)**

5.14.1.2 The focus is to treat the organic cause

Participants also believed that gynaecology doctors are meant to only treat the organic cause behind infertility, and thus is the focus of the consultation. Checking on a patient's emotional status is considered as being beyond their expertise.

> *"Honestly, no, no one asked about my emotions...Because when I first attended the clinic here they only discussed my medical problem and I believe that's what they know best"*
>
> **(28 yrs. 2 years of infertility)**

5.14.1.3 HCPs want to avoid embarrassing patients

Several participants believed that HCPs avoided starting discussions about their emotional wellbeing as it may be considered as being disrespectful to them. These women believed it was embarrassing to them to be asked about their feelings towards pregnancy delay by their treating doctors because it is a sensitive issue culturally.

> *"No...no one asked me that question...no one asked me about any feelings regarding the pregnancy delay...it might be because of the sensitivity of the topic itself, some women don't like to be asked such questions"*
>
> **(27 yrs. 2 years of infertility)**

A few participants were against being asked about their feelings, as they believed it was a private and sensitive issue to them and they do not like to share with others;

> *"I feel that it might make me feel that the one who asks me about it is trying to make fun of me and embarrass me...I don't like it and I don't normally*

answer anyone who asks me about it even in my home...I prefer to keep it between me and myself...even my mother in law, when she asks me about it I don't answer, this subject makes me feel that I am not like other people and inferior to them and don't possess the ability they have to have kids and it hurts me...and make me feel that I'm not like them and they are better than me"

(28 rs. 4 years of infertility)

5.14.2 Providing emotional support is a HCP's personal choice

Some participants referred to certain HCPs who routinely checked on a patient's emotional wellbeing. This led to the conclusion that offering emotional support to patients in fertility clinics is a HCP's personal choice and it depends largely on their personality and their style in treating their patients.

"For the psychological support I think that it depends on the physician herself"

(27 yrs. 5 years of infertility)

"I think it is up to the physician...and their personality to check on patients feelings"

(31 yrs. 10 years of infertility)

A participant shared her experience with a physician who she felt always showed care for her and asked about her emotions each time they met:

"I like her communication style and I felt she knows my situation and understands my feelings and trying to reassure me...it is very rare to meet a physician with this style that cares about your feelings"

(24 rs. 4 years of infertility)

5.14.3 The need for emotional support

The existing need for emotional support was apparent from the interviews with participants. Participants expressed the negative emotions that had originated from experiencing social pressure due to their pregnancy delay and being burdened with the medical treatment of infertility, where they explicitly expressed their need for emotional support. The need for emotional support is further supported from the positive impact of this support among the few patients who have received it. These are discussed below (Appendix G7);

Negative feelings from social pressure

The majority of participants expressed their need for psychological support during their consultations in fertility clinics. They believed this support would help them to be more stable emotionally, which would help them to cope with their infertility. They were hoping to receive this support from the professionals, and to be able to vent about the negative social pressures facing them. However, they were disappointed not to be offered the chance to express their feelings about pregnancy delay when they felt they had the need to.

"It was OK but they didn't pay any attention to the psychological state I was going through from the pressure at home and work because of my

pregnancy delay...honestly...no one calmed me down, because I could imagine that it would have been much easier on me if someone showed some understanding to my feelings and sympathized with me"

(27 yrs. 2 years of pregnancy delay)

Several participants expressed their willingness to open up about their emotions going through pregnancy delay and the journey of treatment, but they would do this only if physicians initiated the discussion

"I don't like to engage in such discussions but if the physician you are dealing with will give you time and attention and talk to you, I will feel that I will be more encouraged to talk with her about my daily struggles and treatment's stress and discuss my emotions"

(22 yrs. 7 years of infertility)

Burdened with fertility treatment

A number of participants expressed the huge burden they felt due to the extensive fertility treatment they receive, and reported feeling drained psychologically. These participants went on to discuss that they struggled to accept the large numbers of pills, injections and medical tests needed, to follow their ovulation response. Moreover, the frequent hospital trips and experiencing strong side effects from the hormonal treatments affected their mood, which was compounded by failed treatment cycles. Going through fertility treatment itself warrants the need for emotional support to be provided to these women, to help them accept and tolerate the treatment better.

A 31 years old participant who had undergone 8 years of fertility treatment (to date) described how difficult the experience had been, especially because it ended up in failure to conceive; this made her think about quitting treatment:

> *"They gave a chance to use some stimulators such as clomid and I continued to use it for several months and of course, nothing happened. Then they took a step higher and told us that they want to start the IUI and for the IUI it was the same thing, in the beginning, we have entirely refused but oh God, the situation we had pushed us to start this experience and I have done the IUI. I have tried 3 times and this was of course after the failed attempts using pills and injections and they all were failed attempts. Then, I mean I had an upset and frustrated feeling and was thinking seriously to quit"*
>
> **(31 yrs. 10 years of infertility)**

Positive experiences and impacts around discussing emotional wellbeing

Feelings of comfort, satisfaction and motivation were common among participants who had the chance to receive psychological support, emphasizing its importance in fertility clinics:

> *"I can feel that Dr. X is more understanding of my feelings she allows me speak to her about certain issues when I'm frustrated, she will encourage me and motivate me and spends enough time with me for me to overcome my stress about the treatment"*
>
> **(24 yrs. 4 years of infertility)**

Similarly, a 19 year old participant who reported that she had received psychological support from her treating physician, mentioned that it helped her bond and open up on issues that she never expected to be able to discuss with the doctor.

> *"She said that I am still very young and made me positive to the point that I don't want to miss the second appointment with her...I was looking for it and reminding myself of it... I mean maybe I was scared to go through treatment and I said what if it fails...she refused this idea completely and asked me; why do you think like that?! she was telling me that Allah(God) will bless you with children and Inshaa Allah (with God's will) you will be happy, moreover she told me if I got a baby girl please call her by my name...this made me very hopeful ,I told her about things I was shy to discuss about like the ovulation time and how I could detect it...sometimes my husband would be on duty during the days of ovulation and when he is here, I get my period so she advised me accordingly, these things I wouldn't have imagined to talk about if she was not this friendly with me"*
>
> **(19 yrs. 1 year of infertility)**

Other participants discussed how important it was for emotional wellbeing to be attended to during the consultation and how simple words of hope and encouragement made a big difference to them.

> *"I will feel comfortable and relaxed if someone asked me about it and might give me hope to continue...it might help them understand me more as a*

person rather than just prescribe medicine and ask me to go and come…go and come…to follow the treatment plan"

(24 yrs. 4 years of infertility)

Another participant shared the impact of receiving emotional support even if it was through few encouraging words.

"There should be a psychologist...you know I usually don't like to speak with anyone about it, I can stay at home for a week if I'm disturbed without talking to anyone...one day I came to take some injections and one of the nurses said "all the best" when she injected me the dose, I felt very happy when she said it...I mean that they are very simple words but they gave me so much hope"

(34 yrs. 4 years of infertility)

5.15 Theme 8: Experience with fertility care service and HCPs

Whilst women in general expressed their overall satisfaction with the available fertility services, given the clinics where the study has been conducted are among the highly specialized fertility clinics in the government sector of the country, improvements were proposed (Appendix G8).

5.15.1 Lack of continuity of care

Most participants were annoyed and disturbed to be followed up by different physicians during their fertility treatment. Normally, new patients meet the senior doctor during their first visit to the clinic. This doctor will order all the required investigations and set the treatment plan, which is followed up by junior doctors

during patient's subsequent visits to the clinic. This process left these participants feeling confused about their treatment. The treatment plan is usually noted in the computer system by the senior doctors. However it might not always be clear to other doctors following up the patients. This requires many of them to ask patients about their medical history all over again. Participants felt this led to time being wasted and that they had to repeat a lot of their history over again with each HCP they encountered.

> *"You know the main problem here that every time I attend the clinic I see a different doctor and I don't see the same one from my first appointment and each one of them will ask me about my story and my medical history. It annoys me that I see different doctor each time...it's a waste of time"*
>
> **(25 yrs. 2 years of infertility)**

A 27 year old participant discussed how being followed up by different physicians might not be safe, because mistakes could be made:

> *"I feel that this is a problem because sometimes the physician whom you are going to see have no idea where I am in the treatment plan and I'll have to explain the whole thing from the beginning...I mean that there is confusion...I mean that even if I know where I am within the treatment plan and understand it well but if it was another patient who is not aware of everything she will accept whatever patients provide and say...one day I have been told that we will start with a certain medication and I have replied to her that I have finished it already"*
>
> **(27 yrs. 5 years of infertility)**

Another participant complained how not seeing the same HCP was irritating. It was considered a barrier preventing patients from bonding with their caregivers, because the main focus would be to catch up with the treatment plan rather than utilizing the available time to understand their patients better;

> *"My name should be assigned to one specific physician and they should adjust my appointments to be with this physician whom I have seen before, because it is different when the physician knows about my case, OK, she will give the treatment accordingly as she reads the notes about my case but she might know me as a person more than the others. Oh God, I don't know about doctor's work, I don't know. Seeing the same physician will help us bond better definitely and feel comfortable, rather than one time I see an Indian physician and the second time an Omani Physician and the other an English one!"*
>
> **(22 yrs. 7 years of infertility)**

5.15.2 Lack of experience among HCPs

An additional limitation in the service offered is the lack of experience and qualifications required for fertility treatment and management by the majority of the treating staff. The number of specialists in fertility (doctors and nurses) is limited compared to the high number of patients visiting these clinics. Participants who follow up with the junior doctors question their competence as they frequently need to refer to the team's senior doctor in conducting the management plan.

"I can feel that the senior doctors explain my case perfectly more than their team. I have noticed they refer to their senior each time I ask anything as they lack the proper experience and knowledge and they cannot take any decision by themselves"

(30 yrs. 4 years of infertility)

"Most of them don't have the proper experience to the point that she asked for some help from a senior physician and this disturbs the consultation and our confidence in them"

(35 yrs. 10 years of infertility)

Moreover, a couple of participants also expressed their disappointment due to the lack of proper guidance from the dieticians they had seen in the clinic. Many women with PCOS and infertility struggle with weight issues that require their referral to dieticians for advice. However, they described the given dietary advice as being inadequate, non-focused and as a result they reported lacking motivation to achieve their weight reduction goals.

"When I attended the last appointment they referred me to the nutrition clinic.... I want them to supply me with a schedule mentioning about what I should eat every day...for example; this is your breakfast, your lunch and your dinner. Or they should say in this month, this is what I should eat and next month I should come and get another meals planner. I mean they should decide the food for me instead of keeping on asking me every time and tell me generally cut on carbohydrates and blah blah blah"

(22 yrs. 7 years of infertility)

5.15.3 Gaps in clinic set up

Almost all of the participants highlighted a number of gaps in the provided care in terms of clinic's set up and look forward for them to be addressed in order to help step up with fertility care in Oman (Appendix G8).

Many participants mentioned the limited access to clinic's services such as scan rooms and finding slots for IUI and other radiological procedures due the high volume of patients attending the clinic. Doctors normally get rushed to empty the scan room for the next patient because the same rooms are used for both pregnant women and those with infertility;

> *"They can add more scan rooms and devices because you need to wait too long for your turn and when it is your turn you will feel like she is rushing the procedure and I feel they want to finish it quickly"*
>
> **(24 yrs. 4 years of infertility)**

A couple of participants also felt privacy needs to be better maintained in the clinic. This is mainly for their husbands when they are required to provide a semen sample either for analysis purposes or for IUI procedure. For the sample to be viable it should be provided no longer than 30 minutes before processing and this requires giving the sample while in the clinic. However, there is no dedicated room within the clinic to do so. Men have to use hospital restrooms which was not considered to be suitable;

"I have noticed that they are missing something...when they do an advanced procedure during the treatment and they would require both partners, I can feel that there is no privacy at all...when they would require a specimen from the husband on the same day and within a short period such as 30 minutes I feel that it is very difficult. I mean that everyone knows that; it is not easy, it is not environmentally prepared and there is no place for the husband to offer the specimen and my husband was annoyed by the procedure in the first time…in the second time, he didn't accept to do the same thing again…and said "I don't like doing it in this way and last time it irritated him for the whole day.""

(27 yrs. 5 years of infertility)

One participant mentioned there was a need to separate pregnant women from those with infertility in the waiting area of the clinic. In her opinion, it is not suitable to mix them up as it hurts her feelings and makes her irritated to sit there and watch and hear pregnant women talking to each other about their pregnancy while she is following up for infertility.

"The privacy should be enhanced here and split the waiting area for the pregnant and non-pregnant women. I mean it's irritating while we are waiting desperately for a baby each time we attend the clinic we are surrounded by pregnant women and their talks about their pregnancies and delivery preparations, especially that we wait for long time in the waiting area and we get exposed to this so often"

(34 yrs. 4 years of infertility)

Finally, as women demand attention be paid to their physical comfort and emotional wellbeing during their visits to fertility clinics, equal attention is needed to step up with the treatment level received in fertility clinics. Women were hoping to have more treatment options for their PCOS condition.

> *"I mean they are still not providing us with more treatment options other than these pills, for example, what about surgery? It is not possible that there is no surgery that can remove the cysts! I am sure there is something they can use to treat this issue"*
>
> **(22 yrs. 7 years of infertility)**

Moreover women wanted fertility clinics to contribute in helping patients seek IVF. They suggested for the government to bear the expenses needed for IVF treatment at least for one trial for the advanced cases who require it.

> *"If they could offer the IVF treatment it would be great because it is very expensive and if I decided to save that amount of money I will need a long time to do so and I can't push my husband because he is burdened with other living expenses"*
>
> **(35 yrs. 10 years of infertility)**

5.16 Discussion

5.16.1 Summary of findings

The psychosocial aspects of infertility

Results from this study showed that culturally, bearing children is viewed as the ultimate goal of marriage and it is a couple's social obligation to procreate. Women are expected to conceive soon after marriage, and that doing so is proof of a man's fertility. As such, women reported experiencing constant societal pressure, particularly from in laws, to conceive. Women were blamed for any delay in pregnancy, and if the reason for infertility was attributed to the man, this was never acknowledged or recognised openly due to the associated stigma.

Women reported being constantly compared to other fertile women and were questioned publicly about their pregnancy delay. Families do not hesitate to suggest their sons remarry, if women fail to conceive. Encouragingly, most of the women mentioned being emotionally supported by their partners. However marital tensions were apparent in couples that had been experiencing infertility for longer, for instance men kept themselves busy at work and often took up various activities in the evenings to stay away from home which were the source of marital tensions.

Having faith and trust in God was a way in which women seemed to deal with their infertility and thus helped them cope with their circumstances, with some discussing how being childless may simply be their destiny. Despite this, participants did not hesitate to reveal the irresistible feelings of loneliness and their jealousy of other fertile women and their husband's attention to family children.

Moreover, they expressed feelings of being inferior to other fertile women and a fear of not experiencing motherhood (as it was an instinctive desire among them) nor having children to look after them in older age.

Whilst women who had been infertile for longer seemed to be coping better, participants revealed using different strategies to help them cope with their infertility. These included occupying themselves by taking up activities, avoiding social gatherings and moving out from their in laws' house, which is considered against the social norms. The social pressure exercised on these women to carry a child is partially sourced to adoption not being the norm in the Omani society and taking up this step is considered socially a confirmation of couple's sterility. Culturally adoption is rejected for reasons related to beliefs of it being prohibited in Islam and rejection of whom these children are or originated from. Given the experienced psychosocial tensions among these women to conceive they start seeking fertility treatment soon after marriage.

Experience with fertility healthcare service

The majority of women start their fertility treatment journey in private clinics. Reasons are related to quick access, privacy and beliefs of the better expertise and the more advanced treatment options. However often they shift to government clinics mainly due to the unaffordable expanses. These women normally carry high expectations accessing these government centres based on other peoples' recommendations and their successful treatment stories.

By experiencing fertility treatment, participants get emotionally and physically drained from the extensive nature of the treatment and the failed conceiving

attempts. However they were disappointed not to have their emotional needs attended to by HCPs nor met during consultations. They referred this to reasons related to limited consultation time due to high patient volumes, the focus on treating the organic cause of infertility, language barriers and the topic's sensitivity to some patients. Better relationships were easily established with nurses whom frequently encounter patients in their follow up visits and spend more time with them compared to physicians who most often lacked continuity of care. However the nurses' role compared to physicians was limited to marginal tasks such as; guiding patients through procedures and arranging for their appointments, while the full authority was to physicians during the consultation process.

Despite a few participants being against sharing their feelings and emotions with HCPs, as it is perceived as socially inappropriate, many others expressed the need to vent their emotions and to be listened to besides treating their medical causes of infertility. This resulted in a positive impact among those who have received support from HCPs who offered it as their personal choice and communication style with patients rather than being a standard of care. Moreover PCOS is associated with increased weight among these women who found weight reduction challenging and frustrating, due to the consequent delays in fertility treatment commencement. This further warrants their need for emotional support to be integrated as part of their routine fertility care.

5.16.2 Comparisons with other studies

Social aspects of infertility

The existing literature on the psychosocial experience of infertility showed that the importance of bearing children differs across the world. The experience of infertility among women from the developed world has mainly affected women's own emotional wellbeing and their identity including how they perceived themselves as real women (159, 160, 162, 164, 165). Whereas studies comprising women from the developing world showed a high level of mental and physical abuse experienced by these women, due to their infertility suggesting the high cultural value given to fertile women in these societies (179-181, 202, 398).

In the developing world bearing children is a normal expectation soon after marriage, and symbolizes a man's fertility and thus his masculinity. Therefore, failure to do so results in these women being abused by their husbands and their in laws (425, 426). While women in this study acknowledged the emotional support received most often from their husbands or families, they were exposed to societal pressures and expectations to conceive, especially from in laws. This involved frequent questioning, often in public settings and accompanied by embarrassing comments, about conceiving and a number of speculated reasons for the perceived delay. Such findings have been reported in other areas of the developing world, such as India (189, 190). Similarly, infertile South African women have also reported being teased at family gatherings and events (186, 188), suggesting that Oman shares a similar sociocultural value towards child bearing. Failure to conceive threatens a man's status. This pushes in laws to try and stand up for their sons by

putting the blame and guilt on women for pregnancy delay as in these cultures it's a woman's duty to provide a child for the family (190). Therefore, as a solution, in laws pressurize their sons to remarry to prove their fertility and help them escape from social stigma especially given that polygamous marriages are allowed in Islam. In contrast, studies from South Africa have revealed a different behaviour where husbands' parents instead pressured their sons to have extramarital affairs only with the hope of conceiving a child (187) , as having more than one wife is against the norm.

Social discrimination against infertile women by means of isolating these women during conversations about pregnancy and childbirth was also observed in this study. Infertile women were also considered untrustworthy in taking care of family children as they lacked the experience to do so which made them feel inferior to other women. Culturally people relate infertility to non-medical causes such as beliefs of couples being envied by others or that they had a curse from an evil eye that stops pregnancy from happening and further beliefs that this curse is transferrable. This attitude was also reported in Rwanda where infertile women are believed to practice witchcraft and bring bad luck to the community and are not invited to childbirth ceremonies(187). In contrast, Omani women were seen to deliberately avoid attending social gatherings especially the ones involving newborns, children or pregnant women to avoid people's comments and questioning leading to social isolation.

Although the majority of women were surprisingly strongly supported by their husbands despite being the reason behind infertility, this support seemed to fade

away the longer the infertility persisted. Several participants with a pregnancy delay of 4 years and more admitted infertility had affected the stability of their marriage. The continuous routine, boredom of staying at home with no children and exposure to people's pressure had weakened the couple's relationship and threatened its stability. In comparison, studies in the developing world reported a more violent response from women's partners/husbands due to their childlessness (188, 189) including domestic violence reported throughout Iran(213). The negative effect of infertility on marriage was also common in the developed world, where divorce was prevalent among married couples with infertility in the United Kingdom and the United States (427, 428).

The value of having children in the Omani society is different to that perceived in the other developing countries. In Oman children are seen as a source of social security in older age rather than a financial source. This might be related to Oman being classified as a middle- income country where people are more secured financially compared to low resources countries. Women in this study revealed their fear not to have children to look after them in older age and thus become socially abandoned, as it is common in the Omani culture for parents to live with their children when they become old. Nursing homes are not the norm in Oman and are rare in existence. In addition, religiously children are obligated to look after their parents at an older age and abandoning them is considered a sin. In contrast, economic consequences of infertility were apparent in studies from the low-income developing world. In India children themselves are viewed as a source of income as child labour is common, and it is an additional source of income which these families are deprived of(429). Similarly, a study from Bangladesh linked infertility

to poverty due to the same reasons related to child labour(430). Moreover, in these countries infertility economically affects women and men. In Nigeria women who do not bear children have no right to inherit their husband's property (431), while in Rwanda men believe infertile women do not have the right to be looked after financially (187). Men especially in rural Indian societies are discriminated against due to their childlessness, which affects their status and therefore their ability to hold a job as a source of earning (429). In comparison, results from this study might suggest couples with infertility earn more compared to those with children. Many of the interviewed women reported themselves and their husbands taking up afternoon jobs or starting their own business in order to occupy themselves after day time working hours in order to escape the boredom and loneliness.

An additional stress factor on these women that might justify society's aggressive behaviour towards their inability to bear children is adoption not being the norm in the Omani society. Many women either did not hear about couples who have adopted or did not have enough knowledge about it. Adopting orphans financially is a common social practice but not raising them. Adoption might be thought of by Western societies as a reasonable available solution for infertile couples to overcome the negative consequences of infertility and its treatment failure(432). However, given the religious and cultural background of the region including Oman, adoption is generally unacceptable. Participants revealed communities' rejection towards adoption, due to many reasons including breaking the family's lineage; the Islamic restrictions and prohibitions around adoption; and the common belief around the origin of these children to be a result of a sinful relationship and therefore a source of stigma and shame in the society. However the common

religious perceptions around adoption in the society are not true, as Islam fully supports taking care of orphanages and Islamic scholars do allow adoption following certain conditions (433). Adoption (in the sense of raising children as one's own) is allowed if adopted child is not given the family name of the adoptive father. In addition adoptive mothers can breast feed her adopted children if they were below 2 years of age to create a foster relationship and thus remove the restrictions between the parents and the adoptive children of the opposite gender after maturity.

Many of the participants in this study reported that adoption is culturally considered a confirmation of a couple's sterility. Similarly infertile women in India said adoption will be considered only as a last option for infertility (434) as there is also a negative family attitude towards child adoption (435). Rejection to adoption was also a common finding in neighbouring countries such as in Kuwait(212),Turkey(214) and Nigeria(194), that are believed to share the same religious and cultural backgrounds with Oman. Despite this, and due to the instinctive desire among women to practice motherhood, the majority of the interviewed women in this study reported adoption as a possible option but only if bearing a child of their own becomes medically impossible. However, they shared a number of concerns to take up this step and these were; fear of lack of compassion towards these children after adoption and limits in using the traditional ways in raising them like beating or scolding as this might be seen as an abusive behaviour, not being their biological children. In addition, women expressed their concerns from being rejected by their adoptive children when they know about their adoption and to have religious restrictions dealing with the ones of the opposite

gender when they grow up into adulthood as they will be considered strangers. Moreover many women shared their concern to be the ones responsible to expose these children to society's discrimination and rejection. A study on barriers to adoption among 240 Iranian couples with infertility reported the unwillingness of 82% of them to adopt(436) . Similar barriers to that shared by participants in our study were found among Iranian couples such as social stigmatization, willingness to self-motherhood and fear not to love them as real parents(436). Iran is an Islamic country and share the same Islamic teachings to that practised in Oman.

Psychological experience of infertility and its management

The psychological suffering of infertility was apparent among the women in this study and was seen to be debilitating. Women complained about being unable to fulfil their desire to bear a child and the faced societal pressure. Prevalent feelings of sadness, sorrow, inferiority to other fertile women and feelings of guilt being the reason behind infertility (in this study due to PCOS) were reported. This psychological suffering was compounded by the experience of going through the extensive fertility treatments and its failures as women who experienced pregnancy ending in miscarriage expressed going through periods of grief and mental breakdown. In contrast, to these findings a study among 120 Kuwaiti women with infertility and an age-matched sample of 125 healthy pregnant women as a control group used Hospital Anxiety and Depression Scale (HADS) to understand their psychosocial status and found significantly higher levels of tension, hostility, anxiety, depression, self-blame and suicidal ideation compared to the control group(212). However the use of a standardized scale to assess the psychosocial

status of infertile women did not help capture the lived experience nor the factors behind their psychological distress. In addition, the use of a control group of a healthy pregnant woman might have inflated their results due to the expected low risk of the outcomes of interest among this group. However in other studies depression and anxiety were still found to be common among women with infertility in different parts of the world due to their childless status regardless of their demographic characteristics or the experienced social pressure (188, 196, 437).

In order to minimise adverse psychological consequences, women in this study adopted different coping mechanisms to live with their infertility. Given the religious context of the region, results in this study have showed women to use their faith in God and destiny to get the strength and support in accepting their pregnancy delay. Many women committed to get closer to God through prayers and being advised to recite specific versus of the holy Quran on a daily basis that are believed to help their prayers get answered and be granted a child.

Studies worldwide have showed women to be the most affected by their infertility and to adopt emotion-focused coping strategies such as crying, praying more and having faith in God. These spiritual and religious beliefs were commonly practised among infertile women in different parts of the world(147, 212, 405, 406, 438, 439). A study involving 24 Turkish women using in depth interviews revealed them to use different religious and spiritual methods to help cope with the psychological consequences of infertility(214).

The other reported coping mechanisms among participants in this study were similar to those reported worldwide among women with infertility who also adopted social adjustment mainly in the form of social isolation and sharing their feelings with other infertile women as they feel less vulnerable around(440-442). It has been generally shown that women who get isolated socially and opt not to share their emotions, cope worse than those who share their feelings with others(443, 444). This was applicable to women in this study who preferred not to share their feelings with the people around in order not to be looked at as inferior. They reported sharing their emotions only with someone very close like a husband, those with a similar status or someone outside their social circle like professionals knowing them to be non-judgmental.

Furthermore this study showed the majority of women adopted a healthy lifestyle through starting on a healthy diet and engaging in physical activity as a way to cope with their infertility. This might be a unique coping mechanism to women with infertility due to PCOS. These women struggle with being overweight. Attempts of these women to reduce their weight and therefore increase their chance to conceive might be the only way for them to feel having control over the situation and decreases their feelings of guilt being the ones responsible for pregnancy delay. Moreover they reported physical activity to help them overcome their stressors and their status of feeling low. A recent case control study in Oman among women with PCOS showed them to be at a higher risk of suffering from stress, anxiety and depression compared to controls. Infertility along with other symptoms of PCOS including overweight, acne and hirsutism were contributing factors to the reported psychological burden(445).

The majority of participants reported initially seeking fertility treatment privately or abroad. Reasons were found to be firstly the quick access to these private clinics avoiding the long waiting list in government hospitals; Secondly, as culturally fertility is associated with stigma, many couples tried to hide their fertility problem and privacy is more assured in private clinics; Thirdly, the common expectations to find more experienced doctors and better treatment options. However going through the extensive investigations and treatment cycles that end up with failure to conceive made treatment costs no longer affordable. Infertility treatment is expensive and women reported to spend 50%-100% of their earnings to try to treat their infertility(446).

Therefore, women in this study who started treatment in private shifted to governmental fertility clinics as a result of depleting their savings. The majority of participants had high expectations accessing these governmental fertility centres due to their good reputation acknowledged by family and friends. In addition, they were surprised to find highly experienced physicians and high standard fertility management that is also free of cost.

However women expressed their frustration going through the extensive fertility treatment and their disappointment from the repeated failed trials to conceive which add to their social strain. Seeking infertility treatment is psychologically a draining experience associated with a lot of tension, stress, pain and disappointment (447-450). The pain and stress associated with infertility were comparable to that experienced by cancer patients (451, 452). Studies have emphasized the importance of psychological support as part of fertility

management given the well reported negative psychological impact of infertility and its treatment on couples especially women (448, 453, 454). However participants were disappointed not to have received any emotional support from HCPs during their medical consultation. Reasons as reported by participants were referred back to lack of time during consultation due to clinic's crowdedness and the focus of HCPs to treat the organic cause. Moreover some patients find the topic to be culturally sensitive and personal causing the HCPs to avoid it not to embarrass patients.

This need for infertility patients to receive emotional support was reported in other studies. A qualitative study involving two support groups of infertile women of two European countries (n=103) emphasized the importance of patient-centred approach during consultation including providing emotional support rather than only focusing on their medical issues (455). Another qualitative study in Denmark involved 16 couples undergoing infertility treatment reported their dissatisfaction with infertility treatment as their emotional needs were not met during consultations(420). This aspect of care as expressed by patients is important to be addressed as highlighted in a study assessing the psychological status of women attending a fertility centre, where a qualified psychiatrist diagnosed 40% of women with a psychiatric disorder(456). The most common symptom was anxiety(23.2%), closely followed by depression(17%) and these disorders did not differ by womens' demographic characteristics nor their duration of infertility(456).

Women in this study trusted doctors' expertise in treating their medical cause of infertility, however they reported finding fertility nurses, especially the local ones,

friendlier and easier to build a rapport with. They encountered them more frequently during their hospital visits and felt they understand their suffering with infertility more than doctors could. Despite this assertion, they expressed nurses' limited role in the clinic compared to doctors who are authorized to steer the consultation process, including explanation of tests and procedures and conveying test results. This limited role of fertility nurses despite them providing more continuity of care to patients was also reported in a qualitative study among Kuwaiti women seeking IVF treatment for their infertility. They wished to have received more education and counselling from fertility nurses whom they shared a stronger bond with compared to doctors (457). Similarly, a few other studies emphasized the important role of fertility nurses in enhancing patients' experiences and satisfaction in IVF fertility centres (458-460). Nurses' role in IVF centres could be considered more important due to the complex nature of these advanced fertility treatment techniques compared to fertility centres with basic treatment options. However, findings from this study showed that nurses' role in fertility clinics regardless of the treatment level offered is crucial.

Studies that have assessed fertility patient's satisfaction with the received care reported their need of a better information provision by HCPs and a better involvement in setting the treatment plan (248, 310, 415, 461) . Moreover the language barrier among the expatriate physicians was an additional reported factor that emphasize the need of a more nurses' involvement in these clinics as many participants will require their help in translation.

In addition, the lack of continuity of care by seeing different physicians during visits to fertility clinics was believed to add to the challenges of rapport building and creates confusion in following the treatment plan making mistakes more likely to occur. In the qualitative study by Dancet et al. participants have also reported their appreciation to have an open clear communication with fertility clinic staff by allowing for enough time for discussions and be open to questions(455). Moreover, some patients preferred absolute continuity of care while other expressed the need of at least a lead physician to follow their treatment plan(455).

The need for psychological support was apparent during women's interviews. The pain, anxiety and stress from going through fertility treatment along with the mood swings from the hormonal treatment had a considerable toll on them. Moreover the external social pressure on these women warrants the need for emotional support.

Many studies support the positive impact of psychological support in improving stress levels among infertile women and therefore pregnancy rates (462, 463). A systematic review by Frederiksen et al. included 39 studies reported the significant positive impact of psychological interventions on pregnancy rates and other psychological symptoms and that these effect size was greater for women than men (464).

Participants appreciated integrating emotional support as part of routine fertility management. Although few participants were against sharing their emotions during consultation as they perceive it as a personal and private issue, they expressed their disappointment not to have received any support when they needed it the most

especially during their experience of miscarriage suggesting support should be tailored to patients' needs. Furthermore the extra psychological and medical challenges faced by infertile women with PCOS, specifically their weight issues suggest their increased need for emotional support compared to other women with infertility. They might further benefit from a holistic approach in their management including being consulted by qualified dieticians. Finally, the presence of this support and its delivery by a psychologist will help overcome the existing barriers for it to be delivered by fertility physicians.

Gaps in fertility care

Further discussions with participants revealed their need to have improvements in clinics' settings to step up with fertility care in these centres. Participants reported more attention should be paid to issues of privacy in the clinic. Firstly, to provide a private room within the clinic for men for semen collection when required as there is no available dedicated place currently for this purpose. Fertility clinics in Oman are dominated by women and men are normally not allowed in unless called by the physician. Participants reported the inconvenience of their husbands to give semen fluid sample in such an environment where most often they either refuse or fail to do so. A study in two fertility centres included 30 Jordanian men, tried to understand the social context of seeking fertility treatment and reported neglect of available fertility service to men's psychological need to provide semen sample(465). This was among the factors that decrease their motivation to seek fertility treatment (465). Secondly, a form of privacy is also needed to isolating women with infertility from pregnant women in the waiting areas. A study reported

watching and hearing conversations among pregnant women is distressing for patients with infertility (414). Finally the majority of participants expressed their wish to upgrade the treatment options within the government settings by providing ARTs namely IVF to those who have failed to conceive trying all available means and who cannot afford its huge cost in private.

5.16.3 Strengths and limitations

In view of the available literature, this study is the first to examine the psychosocial impact of infertility among a group of Omani women with PCOS. It has further assessed the quality of the services in fertility clinics including the extent to which emotional support is offered, where regionally no studies are available yet.

Since the experience of infertility is a phenomenon with both psychological and social dimensions, there was a need for it to be evaluated in the context of the Omani culture. The use of a qualitative study design was the most suitable to get a better understanding of participants' lived experiences (279). The use of a face to face setup, and semi-structured interview guide further allowed the researcher to follow informants' responses and tackle issues raised by them. This has also allowed the interview to be conducted in a flexible, non-formal way to capture the experience as it has been narrated by the participants (301).

Furthermore following a purposive sampling strategy to recruit Omani women with infertility (n=20) from two fertility clinics, of different age groups, place of residence and of different duration of marriage and duration in seeking infertility treatment has provided a source of rich and diverse data to examine the study's objectives and helped data saturation to be attained (297, 302). In addition, including only

women with prior exposure to fertility services to assess their experience with fertility care helped to present a more accurate account of their perceptions and views. The researcher has also followed the proposed guides in implementing "reflexivity"(282) and "bracketing"(291) (see chapter 2,p 45)to eliminate the effect of any prior preconceptions in influencing the research process and thus helped minimize bias and add credibility to the findings (290).

This study also has weaknesses that should be acknowledged. Selecting participants from two of the highly specialized governmental fertility centres in Oman might question the transferability of the findings to women in other rural areas and those treated successfully in private clinics. Women from an urban city like the capital Muscat - and of a higher education level compared to those women from rural areas might not share a similar social experience of pregnancy delay and its treatment. However, the fertility clinics in this study get referrals from different cities in Oman, including from private clinics due to its advanced nature and this is apparent from the included sample in this study. This allowed to capture the experiences of a diverse sample of women.

This study has included only infertile women with PCOS being the cause of their infertility, thus they were the reason behind the pregnancy delay. Therefore, their psychosocial experience with infertility and its treatment might be different to those with male factor infertility or to couples with mutual causes of infertility. Moreover the experience women who have stopped seeking fertility treatment due to their husband's remarriage or those who have not accessed fertility centres for different reasons were not captured in this study. However, this study was the first

of this kind and it presented insightful information about the lived experience of infertility among women in the context of living in the Omani culture. Moreover, assessing their experience with fertility care, which has not been explored before, will lead to further future more diverse studies in this field.

5.16.4 Conclusion and recommendations

The findings of this study have provided knowledge on different aspects of women's experience with infertility in the context of the Omani culture. The obtained data provided a better understanding on how women perceived the social pressure due to their inability to conceive, the impact of childlessness on them and their marital relation and the coping mechanisms adopted to overcome their infertility. Then it has further assessed their experience with receiving fertility treatment and the extent of emotional support offered by HCPs during this process.

In short, Omani women with infertility due to PCOS are experiencing tremendous amount of societal pressure especially from their in laws to conceive. Culturally a high value is placed on women's fertility and it is considered their role to procreate, making them accountable for any pregnancy delay. Moreover failure to getting pregnant prompt in laws to push their sons to terminate the marriage and remarry for a child. Therefore these women tend to seek fertility treatment soon after marriage to satisfy their in laws and protect their marital relationship. However due to the extensive and stressful nature of fertility treatment and the psychological burden associated with not conceiving, participants get disappointed not to have their emotional needs met by HCPs due to a number of professional, organisational and social barriers. Despite this, they continue adhering to the free fertility

treatment in these governmental clinics as they are their final hope especially not being able to afford the costly fertility treatments in private. There is a need for emotional support to be provided through an external source (psychologist) and to be integrated within fertility treatment as a standard of care. This will help overcome the current barriers in providing this support by fertility HCPs. This support is believed to help women better cope with their infertility against societal pressure and better accept and tolerate fertility treatment. The added challenges for women with PCOS dealing with fertility treatments due to their high weight issues, suggest an even greater need for this support that could be achieved by a multidisciplinary team to better address the other comorbidities associated with them.

Future research should focus on shedding more light on the topic of infertility in Oman and the Arabic world which is still considered a taboo and an under-researched area. This should also involve a more rigorous evaluation of the quality of fertility services in these clinics. Studies on cost effectiveness of integrating emotional support as a routine standard of care in these clinics and more evaluation of patient's acceptance to utilise this service are worth considering. These studies will help better support this vulnerable and neglected group of women in our societies. Finally initiatives should be undertaken to raise public awareness about infertility and its psychosocial consequences including the notion of adoption in the Omani society. This will help overcome the taboo socially associated with infertility and help these women get better accepted and supported.

6 Healthcare providers' perceptions of the care provided in fertility clinics

6.1 Introduction

This chapter considers healthcare providers' views and perceptions on the services offered in fertility clinics, including the extent to which they provide emotional support to patients during medical consultations.

The vast majority of studies have examined fertility patients' expectations and satisfaction with the quality of services offered in fertility clinics, including psychological support received during consultations(147, 154, 231, 236, 240, 245, 414, 454, 466-469). However, it is vital to also understand HCPs' perceptions and views on the provision of healthcare services for their patients, in fertility clinics. By comparing and contrasting these accounts, improvements to these services could be recommended and implemented as a result.

Many studies have studied the subject of patient-centred healthcare versus medically-centred care(470-476). Patient centred care has many different dimensions including access to care, continuity of care, involvement of family and friends, emotional support, physical comfort and respect of patients references(477). It is believed that adopting patient-centred approaches during medical consultations is a key factor in considering quality of care(471). Despite the intentions of many HCPs in different fields of medicine to practise such approaches(474), research has revealed that many clinicians fail in doing so. This is reflected in reports that show them failing to address patients' concerns, not sharing or involving them in

management plans and not often checking on patients' understanding of their illness(478). Not adopting a patient-centred approach results in many patients being unable to recall some basic aspects of their medical condition and treatment plan; this occurs partially as care becomes more complex and HCPs give less time to provide information to their patients(478). Patient-centred medical care is reported to help build a better rapport between patients and HCPs(479-482), improve health outcomes(479, 483), increase patients' quality of life (QoL)(480, 482) and reduce costs(481, 483). Areas of medical care associated with intense emotions and long, frequent and extensive treatment journeys, such as fertility treatment might benefit the most from adopting this approach(484). Fertility treatment places both a physical and emotional burden on couples, with reports that 23% of couples visiting a fertility centre in the Netherlands left treatment prematurely due to the demanding psychological and physical impact of fertility treatment(467). This high dissatisfaction with the medical-centred fertility care further supports arguments for adopting more patient-centred approaches in dealing with patients experiencing infertility(485). A cross sectional study by Aarts et al. was carried out to investigate the extent to which fertility HCPs can estimate the level of patient-centeredness using the patient-centeredness questionnaire-infertility (PCQ-infertility), which is composed of 46 questions about patients' experiences with fertility care. Responses from 194 physicians and nurses from 29 Dutch fertility clinics were compared to those of 1189 couples with infertility treated in these centres. The study concluded that HCPs cannot adequately assess their performance on different aspects of patient-centred care as their responses mismatched with what is perceived by their patients(234). Similarly, a qualitative study also conducted in the Netherlands asked HCPs working

in fertility clinics to evaluate the extent to which they incorporated patient-centred approaches to their care, and found that providers' perceptions of their patients' experiences were not in line with patients' actual experience(241). In addition, despite most providers expressing the desire to implement patient-centred approaches, very few clinics had acted on improving this, indicating further steps should be taken to increase providers' motivation to change and improve(241).

As mentioned earlier, assessing the need for and providing emotional support is a dimension of patient-centred care, which has been studied in HCPs using standardized measures, across different healthcare specialities. These studies report a gap(486) and an overestimation of its provision(242, 243) . Very few studies have utilised qualitative methods to consider HCPs' actual views and experiences of providing emotional support to patients(487, 488). A study on oncologists' ability to identify cancer patients in need of psychological support using screening instruments, found HCPs were unable to perceive the psychological distress among their patients; they only recognized 11 out of 30 severely distressed patients and their recommendations for supportive counselling did not correlate with patient distress(487). A cross sectional study using face-to-face or telephone interviews with diabetic patients (n=5104) and HCPs (3827) in 13 countries across Asia, Australia, Europe and North America sought to identify psychosocial problems and barriers to effective diabetes management(488). Providers reported that most patients had psychological problems affecting patients' self-care, yet they reported a lack of resources including time, confidence and proper training to tackle these psychological issues(488).

There is a lack of qualitative studies examining the extent to which emotional support HCPs are giving to patients in fertility. This is an important issue to be addressed given the negative psychological effects of this experience on affected individuals(153, 308). Exploration of the extent of the offered emotional support by HCPs in fertility clinics in Oman will help better understand their views within the cultural background of patients and therefore will help recommendations be tailored to both HCPs' and patients' needs and satisfaction.

This chapter presents the findings of a qualitative study which comprised interviews with HCPs across two fertility clinics in Muscat, where the rest of the research was conducted.

6.1.1 Study rationale

No studies have considered HCPs' views on the quality of care they provide and the provision of emotional support to patients attending their fertility clinics. In particular, to the best of the researcher's knowledge these matters have never been explored in the Middle East, nor have they been explored using qualitative methods. The majority of studies on quality of fertility care have tended to focus on women's and couples' experiences with fertility care or have assessed HCPs' implementation of patient-centred care in general using quantitative measures and standardized scales. Therefore, using qualitative methods in bridging the gap between patients' and HCPs' views on infertility care especially the extent to which

emotional support is provided is vital, given the nature of infertility treatment and its association with both physical and emotional distress among patients. This additional exploration of HCPs' views will provide a better understanding of the current gaps in fertility care and will allow triangulation with findings from the patients' interviews (chapter 5) and will help to identify how this aspect of care could be improved.

Furthermore, this study will be the first assessment of the quality of care in fertility clinics in Oman and results will ultimately be used to recommend interventions that will provide optimal infertility care in the future to this group of women.

6.1.2 Study Aim

This study's aim was to explore HCPs' views and perceptions of the care they provide in fertility clinics in Oman, including the extent to which they address and provide emotional support to their patients.

6.1.3 Study objectives

1. Explore the gaps in fertility care from HCPs' perspectives.

2. Understand how HCPs approach and address infertile patients' emotional needs during medical consultations.

3. To propose recommendations for interventions or care guides for HCPs to enable them to better support infertile patients both physically and emotionally.

6.2 Methods

6.2.1 Study settings

This study was conducted in two tertiary hospitals in the capital city Muscat (Oman): Sultan Qaboos University Hospital (SQUH) and the Royal Hospital (RH). As mentioned in Chapter 4, these two hospitals are the only governmental tertiary hospitals that have highly specialized fertility clinics in Muscat and get referrals from all over the country. Another two governmental secondary fertility centres are available in the same city and countrywide but with limited induction services, where only oral fertility induction medications are offered compared to the more fertility treatment options available in the included fertility centres such as intra uterine insemination (IUI) technique. In recent years private fertility clinics are increasing in number to accommodate the rising numbers of couples seeking fertility treatment, and who cannot withstand the long wait to access government hospitals. These private centres also provide high levels of assisted reproductive techniques (ARTs) including in vitro fertilization (IVF), which are not available in government settings due to the high costs associated with these.

It is worth mentioning that it is the norm for government fertility clinics to be visited by women only. It is not the norm for males to attend. Although husbands' seminal fluids are frequently required in these centres for testing or insemination procedures, men normally prefer to produce samples in private clinics or outside the clinic where privacy is assured. However, if the reason behind infertility is attributable to the male, they will be referred to a tertiary hospital in Muscat that

has a special unit to treat organic causes of male infertility both medically and surgically.

Moreover, most HCPs in fertility clinics in Oman are females, and only one expatriate male physician was employed in one of the included fertility centres when this study was conducted.

6.2.2 Study design

This qualitative study involved a group of HCPs comprising physicians (gynaecologists) and nurses in the two governmental fertility clinics, in Muscat. A semi-structured interview guide (Appendix H3) was prepared with the study objectives in mind and findings from the existing literature, which was used to conduct one-to-one interviews with HCPs. A constructivist approach underpinned the methods and research approach in this study (see chapter 2).

6.2.3 Study population, size and recruitment

As discussed in Chapter 2(p 51) there is no fixed number for consideration when sampling for participants in qualitative research, as richness of the obtained data and data saturation is a better measure than number of participants(489). Therefore, the researcher opted to start with 20 HCPs between physicians and nurses across the two clinics as further discussed and justified in chapter 2 (p 51). All the HCPs were approached and checked for the inclusion criteria (see Table 6.23). Using a purposive approach (see chapter 2, section: Methodological

considerations in qualitative research, p51), the researcher selected HCPs to ensure representation of providers with different job roles (physicians and nurses), levels of qualification, years of experience, genders and nationalities. Based on these criteria, HCPs were contacted either by a phone call, email or text message to be invited into the study. A detailed information sheet was shared with them too (Appendix H1). An interview appointment was arranged with those who agreed to take part in the study.

In SQUH 10 of the 13 HCPs that were approached agreed to take part in the study. While 10 of the 11 approached at RH agreed to participate. Among the physicians who did not take part; one was due to take maternity leave and another (only male physician that was available) hesitated to take part, mainly because he operated in the theatre rather than following up patients in the clinic. In terms of the nurses, 2 opted not to take part in the study. These individuals were expatriates (Indian) and expressed that they did not feel comfortable about taking part because the interview was to be digitally audio recorded.

Table 6.23: Inclusion and exclusion criteria for the selection of healthcare providers

Inclusion criteria	Exclusion criteria
• HCPs working in fertility clinics in SQUH and RH (physicians and nurses) • Both Omani and expatriates in nationality • Have previous experience of working in fertility clinics	• HCPs working in fertility clinics other than SQUH and RH • Recently joined the service (less than a year) and has no previous experience working with fertility patients • HCPs other than physicians or nurses (e.g. dieticians, social workers, radiologists, pharmacists)

6.2.4 Data collection

Data were obtained through conducting face to face interviews with participants using a semi-structured interview guide (see chapter 2 for justification of the selected method, p51). The interview guide was developed based on the research aims and objectives and was also guided by the available literature. Topics in the guide covered the nature of the consultation process in fertility clinics, HCPs' perceptions on current gaps in fertility care, the extent to which emotional wellbeing is explored and emotional support is offered, as well as potential improvements to care including the provision of emotional support (Appendix H3). The guide comprised open-ended questions and probing methods were used as needed to further explore matters raised by participants (as discussed in chapter2). All interviews were scheduled with the HCPs according to their convenience, and were conducted either in a private quiet room in the fertility clinic or in their offices. Participants were given a consent form to sign before the interview

commenced (Appendix H2). This form provided an explanation of the study purpose, confidentiality of the information that would be collected from them, their right to withdraw from the study at any point and their right to ask questions or contact the researcher. The interview guide was piloted with one HCP (excluded from the sample), to check the appropriateness of the guide and the preciseness of the questions. No major changes were made to the guide following piloting.

Interviews were digitally audio-recorded and lasted for 41 minutes on average (ranged from 25 to 74 minutes). Interviews were conducted either in Arabic or English based on each participant's preference.

Audio files and transcripts were stored on a password-protected computer and were only accessible by the research team. All precautions were taken by all those involved to maintain each participant's confidentiality. All participants were given a unique study identification codes and any personal identifiers were removed.

6.2.5 Ethical approval

The researcher obtained separate ethical approvals from each respective hospital site. Ethical approval for SQUH was obtained from Sultan Qaboos University Medical Ethics Committee (Appendix E1). For the RH, ethical approval was obtained from the Ministry of Health-Research and Ethical Review and Approve Committee-Directorate General for Planning and Studies (Appendix E2). Ethical approval was also been obtained from the University of Nottingham's Medical School Ethics Committee (Appendix E3).

6.3 Analysis

6.3.1 Framework analysis

A framework approach was used to analyse the qualitative data in this study. The 6 steps suggested by Gale (423) as outlined in chapter 5 were followed in analysis of this study as well (see chapter 5, section: framework analysis p 142). During the process of analysis data saturation was attained and therefore no more HCPs were recruited. The resulted framework matrices from this process can be found in Appendix (H).

6.4 Results

6.4.1 Participant demographics

Information was collected about HCPs' place of work, job description, gender, nationality and number of years of experience working in fertility clinics; these are summarised in table (6.24). Ten physicians with different specialization degrees in obstetrics and gynaecology from resident to senior consultant were interviewed. The remainder comprised, 10 nurses, where 7 were staff nurses and 3 were fertility specialist nurses. A total of 6 physicians were recruited from SQUH and 4 from RH, while 4 nurses were recruited from SQUH and 6 from RH. All the included fertility HCPs were females as they are the majority in the selected clinics. Most HCPs were Omani (n=12, 60%), with the remainder either Arab (n=3, 15%), Indian (n=3, 15%) or Pakistani (n=2, 10%). The average length of experience for physicians was 8 years (range 1 - 14 years) and 4 years for nurses (range 1 - 8 years).

Table 6.24: Characteristics of healthcare providers (n=20)

Study code	Study hospital*	Medical role	Nationality	Gender	Years of experience
HCP. H1A	Hospital1	Specialist nurse	Omani	female	4
HCP. H1B	Hospital1	Staff nurse	Omani	female	3
HCP. H1C	Hospital1	Specialist doctor	Iraqi	female	11
HCP. 1D	Hospital1	Staff nurse	Omani	female	2
HCP. H1E	Hospital1	Senior consultant	Indian	female	14
HCP. H1F	Hospital1	Specialist doctor	Jordanian	female	7
HCP. H1G	Hospital1	Specialist nurse	Sudanese	female	5
HCP. H1H	Hospital1	Specialist doctor	Indian	female	13
HCP. H1I	Hospital1	Specialist doctor	Pakistani	female	5
HCP. H1J	Hospital1	Specialist doctor	Indian	female	14
HCP. H2A	Hospital2	Staff nurse	Omani	female	8
HCP. H2B	Hospital2	Staff nurse	Omani	female	2
HCP. H2C	Hospital2	Specialist nurse	Omani	female	3
HCP.H2D	Hospital2	Staff nurse	Omani	female	8
HCP.H2E	Hopsital2	Staff nurse	Omani	female	5
HCP.H2F	Hospital2	Senior consultant	Omani	female	4
HCP.H2G	Hospital2	Specialist doctor	Pakistani	female	1
HCP.H2H	Hospital2	Specialist doctor	Omani	female	1
HCP.H2I	Hopsital2	Senior consultant	Omani	female	12
HCP.H2J	Hospital2	Specialist doctor	Omani	female	1

***Hospital name anonymised**

6.5 Healthcare providers' perceptions of the care offered in fertility clinics

Six core themes were generated from the interviews conducted with HCPs. These included; receiving patients in fertility clinics, communication between HCPs and patients during the consultation and treatment process, perceptions of patients' psychosocial wellbeing, identifying and addressing emotional wellbeing among patients, the need for psychological support and challenges to providing better levels of care (Appendix I). Table (6.25) summarises the main themes with the corresponding sub-themes. The remainder of this section will consider each in turn.

Table 6.25: Main themes and sub-themes emerged from interviews with fertility HCPs

Main themes	Sub-themes
1. Receiving patients in fertility clinics	**1.1 Access to fertility clinics** 1.1.1 prior treatment experience **1.2 Nature of fertility clinic** 1.2.1 clinic's schedule and routine 1.2.2 nature of the first appointment
2. Communication between HCPs and patients during the consultation and treatment process	**2.1 Role pf HCPs in the treatment process** 2.1.1 doctor-patient communication **2.2 Role of patients in the treatment process**
3. Perceptions of patients' psychosocial wellbeing	**3.1 Social concerns and expectations around child bearing** **3.2 Medical concerns about fertility treatment** **3.3 Medical concerns specific to patients with PCOS**
4. Identifying and addressing emotional wellbeing among patients	**4.1 Approaching patients' emotions** **4.2 Barriers to approaching patients' emotions** 4.2.1 social barriers to approaching patients' emotions 4.2.2 professional barriers to approaching patients' emotions
5. The need for psychological support	
6. Challenges to providing a better level of fertility care	

6.6 Theme1: Receiving patients in fertility clinics

Initially HCPs provided clarification regarding patients' access to government fertility clinics and the factors contributing to them seeking fertility treatment from these centres. They also provided an account of patients' prior experiences with fertility treatment. Then they provided information on the nature of fertility clinics in terms of their schedule, frequency and nature of the first appointment and what

follow up appointments comprised (Appendix I1). More details are described below.

6.6.1 Access to fertility clinics

Being tertiary health facilities, patients accessed these government fertility centres only through a referral system from local health centres, regional government hospitals, private clinics and internal referrals from other hospital departments. A physician described this:

> *"We have health centres all over in Oman and once the patient goes there some of the health centres do the basic evaluation and then they send us an online referral which we reply and we give them the answer. So, one of the ways is through the health centres. The other way is, I suppose, a patient who's been followed up in one of our hospital's clinic for some other reason and she shows up her desire to get pregnant and get referred. So, it's from health centres, from the private clinics, as well as from our other regional hospitals outside Muscat, so multiple inputs"*
>
> **(Specialist doctor, Pakistani, Hopsital2)**

However, the high volumes of patients accessing the hospital which serves a wide catchment area, results in patients having to wait 3-4 months for their first appointment;

> *"Sometimes they suffer to get the referrals to us, especially if they are from the peripheries and most of the time, they express how much they suffered in order to get into us and most of the time they are happy that they got the*

appointment, the only thing they complain about is that maybe the appointments are far apart because, you know, we're dealing with a large number of referrals in a short time and we are just one or two clinics per week."

(Specialist doctor, Iraqi, Hospital1)

6.6.1.1 Prior patients' experience with fertility treatment

Various factors played a role in patients seeking fertility treatment from these centres or were discussed as reasons for moving from private clinics to the government ones. HCPs described most patients attending their clinics had been experiencing difficulties in conceiving for prolonged periods of time, and that these individuals had also accessed fertility clinics elsewhere in Oman or abroad.

"Most of the time we are getting the chronic patients who are with prolonged infertility, they've got treatment everywhere, so if you already have a diagnosis from outside then it is easier to set a plan of management accordingly"

(Senior consultant, Omani, Hospital 2)

HCPs mentioned that initially many couples preferred to start fertility treatment in private clinics as these offered more privacy and they were less likely to encounter people who they might know. Moreover, HCPs felt that patients believed that private clinics have more experienced physicians and more advanced treatment options.

"It is very rare to see patients come to us and it is their first encounter with infertility treatment, many have done tests elsewhere before mainly in private. They don't want to be seen by others getting treated of infertility problem here and they believe private clinics are better and more private"

(Specialist nurse, Omani, Hospital1)

However, for those who did not succeed in carrying a pregnancy after frequent trials in private clinics seemed to shift to government fertility clinics. Reasons were found to relate to the accumulation of high and unbearable costs of private treatment. Second, couples were influenced by other people's success stories following receiving treatment from these centres, and were hopeful about having a similar positive experience. Thirdly, both SQUH and RH are viewed as reputable tertiary hospitals in the country with highly specialized fertility physicians and up to date fertility equipment and treatment options, which can be accessed for free:

"Most of them are very confident that they are coming to the clinic and will become pregnant after the treatment...based on other people recommendations...it could be based on the consultants' and hospitals' good reputation...that encourage them the most...and it is free, they speak about several patients who they know they have attended here and got pregnant later on.so they believe in us"

(Staff nurse, Omani, Hospital2)

6.6.2 Nature of fertility clinic

6.6.2.1 Clinic's schedule and routine

HCPs provided an insight into the nature of fertility treatment in the centres where the study was conducted. The two clinics in SQUH and RH shared similar care systems. Both had two senior consultants specialized in infertility leading fertility clinics twice a week, with their teams of doctors. In each clinic there was a mixture of booked new and follow up cases. There was always a lower number of new cases ranging from 4-6 compared to 10-12 follow up cases. HCPs spent more time with new cases – 20-40 minutes compared to 10-15 minutes for follow ups. However, physicians see much higher numbers of patients than those scheduled, due to walk-in patients who have to come for particular tests or scans that are done on certain days of their menstrual cycle. Walk-in patients visit the clinic daily and are required to be seen by other non- fertility physicians (Appendix I1).

> *"Usually the infertility clinics are run by two consultants, so they have a speciality clinic two days in a week. Sometimes patients come on the other days also, because of follicular tracking, they may come on any day. So, roughly around 15-16 patients in a clinic on a day, on a daily basis for both consultants. So, maybe in a week around 30 patients in infertility clinic. This may include first visit, plus follow-ups, in a clinic maybe around four or five new patients, and the rest may be follow-ups. First visit takes time, it may take around 15-20 minutes for a patient. Plus, scan and all that. So, follow-ups takes lesser time, because we have already the plan and things sorted out."*
>
> **(Specialist doctor, Indian, Hospital1)**

6.6.2.2 Nature of the first appointment

In the first visit to fertility clinics new cases go through an extensive history taking process, full physical examination and some basic investigations including ultrasound imaging of the uterus and ovaries, a pap smear test and basic blood workup. These patients are given an appointment to do the histosalpingogram (HSG) test which is a radiological test using a contrast substance done in the radiology department to check the patency of the fallopian tubes. Patients will usually have their husband's seminal fluid collected for testing in a private clinic and will only bring the result of it, as it is not the norm for husbands to attend the fertility clinics, which are dominated by women.

> *"During the first visit, they take the full medical history for her and the husband along with the social history and then will start with the primary investigations such as pap smear and scanning and she should have brought the semen analysis report from the health centre or private as many don't like to do it here...we also do the hormonal blood tests such as FSH, LH and some of them do it on the 2nd day of the menstrual period"*
>
> **(Staff nurse, Omani, Hospital2)**

A primary plan will normally be set from the first visit especially for those with test results done elsewhere prior to their visit to these clinics. This plan can later be modified based on investigation results. Patients will then be given a follow up appointment that might take up to 2-3 months as radiological department tests take time to be scheduled due to the big load of patients.

"Patients will be given another appointment after 2-3 months to trace all the results as they would be ready only by then and develop the proper diagnosis to be able to plan the treatment"

(Specialist nurse, Omani, Hospital1)

6.7 Theme 2: Communication between HCPs and patients during the consultation and treatment process

Interviews revealed different aspects of HCPs communication with their patients during the medical consultation, these include the role physicians and nurses play in the treatment process, which covered the challenges in information provision and the expected role of patients during the treatment process (Appendix I2). These are discussed in turn below.

6.7.1 Role of HCPs in the treatment process

Results revealed the extensive role of physicians compared to nurses in the consultation and treatment process. The consultations are mainly doctor-led. Doctors are authorized to explain to patients the reason behind their infertility, order and explain the clinical tests and procedures and convey test results. There were differences in the role of nurses depending whether a nurse is a staff or a specialist nurse. Staff nurses play a very marginal role in the clinic, focusing mainly on administrative tasks. Staff nurses are responsible for checking patients' vitals when they first attend, guiding them in the clinic, booking their follow up appointments and only assisting physicians during scans and medical procedures. They are not authorized to be involved in explaining procedures to patients, taking their consent for procedures, conveying test results or participating in performing

clinic-based procedures as they lack the required training. A staff nurse explained her role in the clinic;

> *"I am here to see the list of patients who have been given an appointment on one of the clinics day…so, at the beginning we see the appointment list and then we measure the blood pressure, weight, height, pulse and O_2 saturation for them, then we let them wait to see the doctor, once the physicians arrive, we start calling patient to attend the physician's room and assist them during the procedures. As a staff nurse, I don't contact the patient and physicians who explain to them everything. It is the physicians...the authority is only for physicians or for the specialist nurse to tell the patients about the results. Moreover, she gives them full explanation about the IUI...it might be due to the job description that prevents us from sharing and discussing medical information with patients"*
>
> **(Staff nurse, Omani, Hospital1)**

Specialist nurses are more qualified than staff nurses, and therefore are given more tasks in the clinic. They are authorized to order some tests for patients and follow them up more closely by explaining to them the nature of their disease and the medical procedures further, particularly if they could not comprehend these during their consultation with the doctor. They also prepare patients and seminal fluid for IUI procedures, that they are trained to perform if required;

> *"There are always infertility nurses who know what exactly those patients' needs, for example, if I said that this patient needs more investigations at day 2 and day 21 and HSG, she will start taking a brief history such as the*

menstrual period timings etc... and will tell the patient what is required to do on that day... when she comes on day 2, she will say when is her day 10 to arrange another procedure on day 10 to see how are the tubes and she will remind the physician about the required investigations for the patient...and for the IUI, they usually prepare the patient completely such as the semen that will be prepared and cleaned and usually she will also inject it"

(Specialist doctor, Sudanese, Hospital1)

6.7.1.1 Doctor-patient communication

Further discussions with HCPs revealed some obstacles that threatened an optimal level of communication between themselves and patients. The majority of HCPs expressed how fertility patients struggle to comprehend the treatment plan during consultations. Given that physicians have to explain the management plan within the context of large numbers of patients to see, time is limited for them to exchange information with patients, especially because fertility treatment is extensive in its nature. This leads patients to go back to nurses after the consultation to repeat the management plan. Nurses also reported that patients frequently call the clinic for further clarification regarding their treatment, which consumes a lot of medical staff's time and energy;

"To be honest, I don't think they are spending enough time with the consultant to discuss their conditions because of the overload we experience here...patients might have the time to ask but I feel that it is insufficient...insufficient...the physician, during the consultation try to

explain everything needed in a short time and sometimes some patients don't understand what has been said to them and come to the nurses to ask and we will explain again"

(Staff nurse, Omani, Hospital2)

The language barrier was reported as a second factor that contributed to the limited comprehension of treatment plans among patients. Many HCPs including those who are expatriates where Arabic is not their first language, admitted the difficulty in explaining treatment plans to patients who do not know English; hence in these situations they require the Omani nurses' help in translation. However, these nurses are not always available to help due to staff shortages:

"Most of the patients like to attend the Omani physicians because they want to understand and discuss their condition with the physician otherwise they are not comfortable to see the non-Omani physicians...and sometimes they are annoyed to talk to me to translate to the physician and the physician will explain and answer me and I will translate it back to the patients and they feel they are wasting their time"

(Staff nurse, Omani, Hospital2)

Moreover, many HCPs mentioned their reliance on verbally communicating medical information to their patients without the use of leaflets or any other visual illustration materials. This was due either to the unavailability of these materials or their availability in English language, which most patients do not understand. Few HCPs used a medical atlas to help patients visualize the procedures. A specialist

doctor who trained abroad emphasized the need to use illustrative materials in fertility clinics to help patients understand better;

> *"As I told you, sometimes we need to work out some leaflets, because in infertility we are limited in this, diseases like polycystic ovary, endometriosis need more explanation. Sometimes the patients don't understand, and they have to go through the internet and learn a lot of things there which might not be right. So, I think we have to work more on leaflets. It will be very helpful for them"*
>
> **(Specialist doctor, Omani, Hospital2)**

Moreover, the lack of continuity of care in the clinic where patients do not see the same physician during their visits was reported to threaten rapport building. HCPs believed that lack of continuity of care also creates confusion in terms of the treatment plan and affects a doctor's competence, as many junior doctors are less qualified and mentioned their need to follow the documented plan set by the senior doctors or consult them constantly during the management process.

6.7.2 Role of patients in the treatment process

When HCPs were asked about patients' roles in the treatment process, a number of them believed that they should comply with the management plan set by the doctors through showing up for their appointments and by taking their medications on time as prescribed (Appendix I2). A HCP said;

> *"The patients' role is to give us a complete history, they are encouraged to come with papers or investigations reports, the radiological investigations*

and other surgical procedures they have had, the medications they have been prescribed and they have taken. So the patients' role is essentially to give us all the information they have with them, and then they have to cooperate with us for a complete examination"

(Senior consultant, Indian, Hopsital1)

HCPs expressed that most patients are mainly receivers and were passive when it came to setting the treatment plan; they referred this to different reasons. First, patients trust the experience of the HCPs in these tertiary centres and believe they decide the best for them. Second, HCPs believe patients' involvement in medical plans depends on their educational level, as those highly educated will have read about their problem and the treatment options available and might discuss this further with HCPs, compared to those who are less educated.

"I think it will depend on the education of the patient we are dealing with, some of them are really interested and want to know why things are being done, others who are really curious have read up from Google and they will ask questions, the others are just listening to whatever we suggest and they are ready to follow the investigations, maybe it is just their level of education or their level of understanding, that they feel you are the doctor and you know what is to be done and they won't really want to take the trouble to understand."

(Specialist doctor, Indian, Hospital1)

A patient's age and duration of infertility was also discussed as playing a role in their involvement in the consultation process. Patients approaching their mid-30s

and 40s of age and those with a longer period of infertility who have been exposed to different fertility treatments are generally more anxious to conceive.

> *"Most of the people who are approaching 40 years old are highly likely to discuss it...It might be the fear of approaching the menopause period and not responding to the treatment, and I think they discuss the treatment plan because they have been treated before and know more about it"*
>
> **(Staff nurse, Omani, Hospital2)**

6.8 Theme3: Perceptions of patients' psychosocial wellbeing

Interviews with HCPs showed that they are aware of patients' psychological wellbeing, through conversations during medical consultations. During analysis, wellbeing was discussed in relation to three categories: social concerns about pregnancy delay, medical concerns about going through fertility treatment and medical concerns specific to those with PCOS. Each of these sub-themes is discussed in turn below.

6.8.1 Social concerns and expectations around child bearing

Both local and expatriate HCPs acknowledged the social pressures faced by women going through difficulties to conceive (Appendix I3). Most HCPs mentioned women being anxious and stressed when they visited fertility clinics. This related to societal pressures on them, especially from their in laws to conceive, or constant questioning and pressure to seek fertility treatment. An expatriate HCP was shocked to see a woman seeking fertility treatment early after marriage and being anxious about it, despite being young in age;

"I remember a very young patient, she was barely 20, married at the age of 18 or 19, she was not married for too long, so it surprised me that she was seeking treatment for infertility and when I told her that by definition, "You don't fulfil the criteria for infertility so you don't need treatment", she got really upset and she started crying, to the extent that I had to close the door and sit with her and ask her why that desperation and that's when it came out, like her mother in law was harassing her, about the delay in pregnancy"

(Specialist doctor, Indian, Hospital1)

HCPs perceived that these women were concerned that their husbands may remarry to prove their fertility. HCPs mentioned that these women were exposed to comments from their mothers in law indicating the need to look for a new bride for their sons, due to not being able to conceive.

"Yes, most of them, the pregnancy delays in our community are now defined as a stigma. I mean if she is not pregnant within the first 6 months of the marriage, everyone starts to push such as her husband or her family or her husband's family...everyone in the community asks her whether she becomes pregnant or not and this makes her feel stressed and she must treat it. Women always complain of receiving hints from their in laws to start looking for a new bride to their son if they don't get treated soon from infertility"

(Specialist nurse, Omani, Hopsital1)

In further discussions, several HCPs revealed that some women seek fertility treatment secretly and part of their stress and anxiety is related to them trying to

hide and not wanting to be seen in fertility clinics by their friends and relatives as it is stigmatizing culturally. A nurse from SQUH described this;

> *"While for infertile patients, the community is not accepting them yet, we are a small community here and they might bump into women they know coming for pregnancy follow up so they don't want others to know what she is following up for ,you can feel that patients don't like to hear the word "infertility"...they don't want even the receptionist to mention the word "infertility" to prevent the audience from being aware that she is suffering from a pregnancy delay problem, and now most people are educated and know what does this mean if it was pronounced in English"*
>
> **(Specialist nurse, Omani, Hopsital1)**

In addition, HCPs agreed that they had observed how it was perceived as socially humiliating for men to be blamed for infertility and it is considered a stigma to their manhood and masculinity. Therefore, they refuse most often to attend the clinic for investigations and it is much easier to put the blame on women for the pregnancy delay than to be labelled infertile. Some HCPs reported that some women try to conceal their husband's infertility and accept blame themselves, despite knowing the defect to be from their husbands which adds to their stress level;

> *"It happened two days ago that I am saying to the patient that she is fine and it is very clear that her husband who has the problem, but she insists that she needs a treatment... sometimes the community is accusing the women to be guilty. Second thing, women in our community are very humble*

and know that fertility among men is related more to their dominance and their masculine and don't want to show anyone that their husbands detract from their manhood, we still have this notion that forms a barrier"

(Specialist doctor, Pakistani, Hopsital2)

6.8.2 Medical concerns about fertility treatment

HCPs shared the common medical concerns among women attending for fertility treatment (Appendix I3), some of which related to increasing age and the associated challenges of conceiving. Others were disappointed not to find IVF in these centres, which added to their stress and anxiety - being unable to afford its expenses in private clinics.

"We are lacking IVF which most of patients are dreaming of, as IVF increases their chances to conceive quicker, but we don't have it, when they come they have the impression that X hospital is a tertiary hospital and apparently it has the IVF service, so, they will be shocked when they know that we don't have it here and of course this breaks them as it was their only hope"

(Staff nurse, Omani, Hospital1)

The most common issue was that women tended to rush the treatment process, as most of them would have been treated elsewhere and went through the same tests and investigations. In these cases, HCPs reported that women are disappointed when they find out they have to repeat the tests all over again, which is often time consuming in the government setting due to the high volume of patients accessing these centres. Others are reported to be emotionally drained from treatment

failures elsewhere and thus come with low hopes and expectations of any success to conceive. However, others are desperate and are hanging on to the opportunity as a last hope, as they cannot afford treatment elsewhere. A staff nurse said;

> *"Most of them are expecting that they will start the treatment process immediately and the major shock happens when we tell them to repeat all the investigations, the problem that investigations are consuming a considerable time until they are done because it should be taken during the next cycle of the menstrual period, then, she has to book the radiological imaging which will be scheduled only after another one month and a half….so they are stressed as a result of the time wasted and they tend to be in a rush"*
>
> **(Specialist doctor, Sudanese, Hospital1)**

Other common medical concerns among patients attending fertility clinics other than fearing pain from certain procedures is their concern about IUI procedure specifically. IUI is the highest level of fertility treatment offered in these centres and a number of HCPs shared patients' concerns to go through the procedure. Women's husbands either refuse due to their belief that IUI is prohibited in Islam while others fear the mixing up of semen fluid samples with that of other patients. A HCP mentioned;

> *"Some religious husbands which I have found they have this thinking that maybe it is not something good or prohibited, but then when we talk to the patient we tell them, it's like they're more specifically concerned about this thing that what if two samples get mixed? , "How you are going to know*

that this is my husband's sample?" So, then we reassure them that at the time of IUI it's only one couple there. There is no other couple, no other sample. So, that is the most specific point where the husbands and the couple, are more worried about"

(Specialist doctor, Jordanian, Hospital1)

Few HCPs mentioned women to be less aware of the risks that accompany multiple gestations as a result of induction treatment. Many women instead perceive it as an advantage and other women might wish or ask specifically to increase their chances to have multiple gestations;

"They'll just tell you whatever you think is fine, just go ahead with it. I'm telling them about the risk of the stimulation, and the risk of twin pregnancy, instead of worrying they say "Okay, it's fine, It's okay with us" they are happy and take it as an advantage"

(Senior consultant, Indian, Hospital1)

6.8.3 Medical concerns specific to patients with PCOS

Common medical concerns were perceived by the interviewed HCPs among women with infertility due to PCOS compared to women with other causes of infertility. The most frequent complaint among these women is their struggle to lose weight, as high BMI is a common symptom among infertile women with PCOS. Many HCPs mentioned that these women need to reduce their weight prior to commencement of their fertility treatment, but that they struggled and that this affected their emotional wellbeing;

"If it is like polycystic ovarian syndrome, more of patient involvement is required, because first line is weight reduction. So, we want patients to cooperate with us in having the weight reduction but they are unable to reduce the weight, that's a major issue for them. We advise, but then they're not able to, which make us feel that they are emotionally disturbed"

(Specialist doctor, Pakistani, Hospital1)

Another medical concern among infertile women with PCOS, reported by HCPs is that they respond much slower to fertility induction treatment compared to other infertile women. They are also more prone to react negatively to treatment by developing uterine hyper stimulation syndrome which is a life-threatening condition. Moreover, if they succeed in carrying a pregnancy they are considered more challenging as they are at a higher risk of complications such as miscarriage, preterm delivery and other comorbidities such as gestational diabetes and pregnancy induced hypertension. A physician discussed the challenge of treating women with PCOS;

"Polycystic ovarian syndrome, they are more challenging in general, they are at a higher risk of not responding to ovulation induction or having ovarian hyper-stimulation syndrome in response to treatment, so that is an extra additional challenge when it comes to it because their menstruation is also a problem as they don't ovulate, obesity is a big part of PCOS that they need to lose weight and it is not easy, even when they get pregnant then issues of diabetes and hypertension is there, so there are quite a few factors which make infertility in PCOS a little more challenging than others."

(Specialist doctor, Omani, Hopsital2)

Due to all these challenging issues, women with PCOS are seen earlier in fertility clinics after marriage compared to those without PCOS, as most of them would have been diagnosed during puberty and know they would need help to conceive and that this might take a considerable length of time. A nurse explains this;

> *"Most of the patients want to get pregnant at the first year of marriage and they might be deferred back if they haven't completed a year unless there is an essential problem such as PCOS, we accept to treat them early after marriage, they are mostly depressed because they know the struggle to conceive right after they marry as mostly get diagnosed earlier during puberty"*
>
> **(Specialist nurse, Omani, Hospital1)**

6.9 Theme4: Identifying and addressing emotional wellbeing among patients

Most of the HCPs were aware of the emotional distress experienced among women with infertility, due to the social pressures and medical burden of fertility treatment. Further discussion took place to clarify their role in addressing these issues. Results revealed different approaches used by HCPs to cover patients' psychological wellbeing. In addition, many professional and social barriers were identified that challenged properly handling these emotions during medical consultations in fertility clinics (Appendix I4).

6.9.1 Approaching patients' emotions

When discussing emotional support offered by HCPs, several interpreted this more in practical terms. For instance, many HCPs mentioned being supportive by trying to

optimize the services offered to patients to ease their journey going through fertility treatment. These were through being flexible and seeing them on days other than their appointment days, applying appointment system to reduce their waiting time to see the doctor, providing scans in the clinic and sometimes accept not to repeat tests if done earlier in private to accelerate the treatment process (Appendix I4). A nurse expressed this level of support as the maximum she can provide to patients;

> *"We support them by starting with their blood tests and scanning procedures firstly to be able to allow them leave early as they come so frequent and sometimes we start with the next step of the treatment plan earlier, for example, if she has to take some medication on the 2nd day of menstrual period, we would give her the prescription already on the previous visit to avoid coming twice at the hospital and because most of them live very far and tell them to come late at the appointment day because it is very crowded in the morning so they don't have to wait long to see the doctor"*
>
> **(Staff nurse, Omani, Hospital1)**

While other HCPs believed that their way of communicating with patients was by being gentle and using sympathizing facial and body language to provide indirect support to these patients. A physician shared her approach;

> *"I think it is the empathy that we show, it is the way we speak to them and the way we try to ask them questions, it is not as if we're trying to dig into their personal history. I think maybe by the body language of the doctor or*

the way they are talking would show enough sympathy and will help patient feel supported"

(Specialist doctor, Indian, Hospital1)

Many HCPs were honest and mentioned that directly enquiring about patients' emotional wellbeing is not part of routine practice, in fertility clinics. However, HCPs did report attending to patients' emotional status if patients expressed how they were feeling or were visibly distressed or upset, which was exhibited by becoming tearful or angry;

"It is only occasionally when some of them come and talk to me to tell me that they feel down or pressurized ...etc., as a result, I listen to them and will give them chance to express her feelings and if we can do anything to help we will do, other than that to be honest it is not a routine to check on patients' feelings"

(Staff nurse, Omani, Hospital1)

Results also showed that some HCPs routinely checked on their patients' emotional and social status, through their own personal choice and style of consulting patients rather than a standard unified practise. This was a common practise among those with more experience of working in fertility care and those who were highly qualified (e.g. physicians). A senior consultant mentioned;

"when I see them I usually ask them how they think about it and what do they expect and how are the investigations and through the questions, I can understand if they are worried or concerned and how it is affecting their life

and their relationship and whether there is any stress in their life or not and basically if you are a physician you should do it naturally and be smart, I find it easy and I cannot see any barriers at least for me.....I believe it is your own way to give them the impression that you are caring and it depends on the way of communication and how comfortable you make them to open up and talk, but generally I feel it is fine"

(Senior consultant, Omani, Hospital2)

When forms of the offered emotional support in the clinic was further explored, HCPs mentioned that if provoked they do support patients using different methods including; giving patients more time during consultations than scheduled to allow them express their feelings, encourage them using gentle words to continue the treatment, remind them of their destiny and God's will especially that it is a religious community who have faith in God and find these words consoling. A physician narrated how she reacted in the clinic to an emotionally distressed patient;

"She cried when I asked her about her husband because she said as long as he doesn't have any deficiency he refused to do any investigations, and the fault is hers so, she was broken and down and I left her to express her feelings and take her time to cry and I tried to convince her that infertility is not due to one person's fault, it is coming from two persons and I told her that you don't have any problem and it is his problem;...and she calmed down, so in these situations I often give them time to express their feelings, advise them and use nice words "

(Senior consultant, Omani, Hopsital2)

From the interviews with HCPs it was noted that in general approaching patients' emotions was easier among Omani nurses where they were found to be friendlier and have a stronger rapport with patients as they see them more often during their frequent visits compared to physicians. A senior staff nurse with 5 years' experience in the fertility clinic said;

> *"Honestly speaking I feel that patients are trusting the nurses more than the physicians...physicians explain everything and patients return back to the nurse to ask them about what have been told due to the trust and rapport they have...another point, when the patient comes again to do the procedure on another day, it will be explained to them again by the nurse....my expatriate colleagues are doing very well, but I feel the Omani nurses are more of friends and sisters to the patients, we see them so frequently and they feel easier to open up with us"*
>
> **(Staff nurse, Omani, Hospital2)**

6.9.2 Barriers to approaching patients' emotions

HCPs mentioned a number of barriers that prevented them from providing emotional support and counselling to patients in fertility clinics, during medical consultations (Appendix I5). Analysis grouped these barriers into professional and social barriers, each of which is further discussed below.

6.9.2.1 Professional barriers to approaching patients' emotions

Many HCPs agreed that the amount of time for consultations was limited, given the high volume of patients to be seen which makes it difficult to check on patients' emotions; which they felt would require a considerable amount of time to discuss (Appendix I5). A senior consultant explained how this support is easily offered to her patients in her private clinic where she works extra time but very difficult to implement in the government set up;

> *"Honestly, they might try to speak but we don't give them the chance to speak about it...because we don't have time and it really hurts me...for example, if I treat patient in a private clinic, I will give her 30 minutes easily and speak about other aspects but we cannot do this in government hospital due to the load we have of patients"*
>
> **(Senior consultant, Omani, Hospital2)**

A second barrier among expatriate HCPs was the language barrier. Many of them are English speaking physicians and their use and understanding of Arabic is very weak. As such, these individuals mentioned that this made it difficult for them to touch upon topics to do with patients' psychological wellbeing;

> *"I guess we are comfortable in touching upon that, except for some maybe language barriers sometimes. We can't ask that very personal questions when it comes, because we're expatiates, and we ask medical terms yes, but when it comes to too much of emotional, then we might find it difficult"*
>
> **(Senior consultant, Indian, Hospital1)**

Other HCPs mentioned that they lack the proper training to offer psychological support, even if they had the time to do so. Participants felt they were trained to deal with the organic causes of infertility. Despite this, HCPs did express a need for such training;

> *"In our training and all doctors' training, we didn't learn, or no one emphasized on how to touch patients' hearts, how to deal with depressed patients. How to deal with aggressive patients. Maybe we were taught about it in a class or as a subject, but we were not properly trained. I think this is important, this is very important, and we should change the system, so it is patient centred care and not illness centred to improve the quality."*
>
> **(Specialist doctor, Omani, Hospital2)**

Another fertility speciality nurse with special training in psychiatry said;

> *"The physicians don't know how to assess those patients mentally and I am able to holistically assess patients with depression and once I knew that a patient was depressed and I have informed the physician about her and she referred her and recommended to be seen by the psychiatrist, this was a case. I was the one advising the physician to refer her, as gynaecology doctors are not properly trained to diagnose depression"*
>
> **(Specialist nurse, Omani, Hospital1)**

A few HCPs shared an institutional factor that served as barrier to supporting patients better, where a behavioural medicine department was unavailable in the hospital compared to the other hospital. This was considered as an extra challenge

for HCPs as they needed to refer patients to another hospital to receive psychological support, as appropriate.

> *"We don't have the service in the hospital and the only facility is the psychiatric hospital that supports them, but it is a very long long way to go there from here and it is a big hassle to refer patients there if their condition is not serious, so we support what they are facing and tell them to inform the family and to share it with her mother or sister who can manage the situation and support her..."*
>
> **(Specialist doctor, Omani, Hopsital2)**

Despite that, HCPs mentioned that patient referrals to psychiatry departments were rare. HCPs would normally refer only in cases of clinical depression where they observed a need for these patients to be on antidepressants, which is not common among women with infertility. A physician said;

> *"We can refer to psychiatry, but never happened to me. I never sent a patient to psychiatrist. I didn't see any patient reach that stage, like in a medical depression. So, I never sent to a psychiatry, we sent a patient to psychiatry before, but it was for endometriosis, severe pain, whatever, but not because of infertility"*
>
> **(Senior consultant, Omani, Hopsital2)**

HCPs believed infertile women just feel down and pressurized, where they need the help of a psychologist rather than a psychiatrist. A physician when asked if she had ever referred a fertility patient to a psychiatry department said;

"No, not really, I can't remember referring anybody for psychiatric help, there's a difference between psychiatry and social services and emotional support, psychiatry is where I would really be worried about her, not the social pressures but about her psychological condition, not as in because of the stresses but where I really think there's some pathology which is affecting her, that's totally different, so I don't remember referring anybody to a psychiatrist."

(Specialist doctor, Indian, Hopsital1)

6.9.2.2 Social barriers to approaching patients' emotions

HCPs mentioned social constraints around checking on emotional wellbeing of fertility patients attending their clinics. HCPs described that patients attend the clinic expecting biomedical treatment. Some HCPs perceived digging into patients' emotional wellbeing might be considered as being intrusive to some women (Appendix I5). A staff nurse mentioned;

"Some patients don't like to talk about their personal or family issues and some of them don't even speak to their sisters about what happened between her and her husband...and they feel it is not appropriate to be shared with the medical team as these issues are very personal"

(Staff nurse, Omani, Hopsital1)

On the other hand, a few HCPs believed that women preferred to be supported by people from their own social circle, such as their husband, family members and friends, rather than from professionals who are considered strangers, or that they

were responsible for addressing only the biomedical cause of their infertility. A physician indicated this;

> *"We are a Muslim country so you know the situation. Still we are getting family support, mother is supporting, sister is supporting, friends are supporting. Most of the husbands nowadays are supporting. We are different from the old days. What I'm seeing now, most of the husbands are supporting…really. So, the hospital we don't have like social worker to go and counsel we don't have it. I think women are more comfortable to share their feelings with their families than to us"*
>
> **(Senior consultant, Omani, Hospital2)**

In addition, many HCPs expressed that some patients were hesitant about accepting emotional support from psychologists when offered. Culturally, visiting a psychologist is still associated with notions of being mentally ill or unstable. Most often the word "crazy" is associated with those who attend psychiatry department. Moreover, HCPs mentioned people in the Omani community are close to each other and it can be easily spread to others if someone is attending such services, which is why many avoid it, as it is stigmatizing;

> *"But some people will not like it because they might think that we are accusing her of being crazy and it is going to be an issue when their husbands find out because our society is a blaming society and they think that she is infertile and crazy and this is the usual scenario to be honest"*
>
> **(Specialist nurse, Omani, Hospital1)**

6.10 Theme 5:The need for psychological support

Further analysis of HCPs' interviews revealed that they did feel a need to provide emotional support to women in fertility clinics. Many reasons were proposed for this by the HCPs (Appendix I5). Firstly, HCPs were found to understand the amount of social pressures facing women with infertility. HCPs felt that many women needed the space to vent these feelings;

> *"Yeah, they are very open and comfortable. You feel they need to speak to somebody, like they feel relaxed when they speak about the pressure they are going through at home, and they thank you for listening and allowing them to talk. Sometimes they ask for your phone number, just like a sister to talk to them. They get attached to you they want to speak it out but it is not always possible here"*
>
> **(Specialist doctor, Omani, Hopsital2)**

Secondly, HCPs revealed the burden of fertility treatment itself warranted the provision of emotional support. Patients are desperate to conceive and are considered lucky to have the opportunity to be treated in these centres so they push themselves to the limit in the hope of conceiving. HCPs described patients' disappointment from failed treatment trials and the emotional ups and downs they endured, due to the hormonal consequences of fertility medications. A staff nurse said;

> *"You can feel they are already tired emotionally from the treatment and from the long delays and have visited many clinics and tried many things.... it is not easy to have all these hormonal medications and injections and then end up with failed conceiving attempts, it is a lot for patients emotionally,*

they need a psychologist to help them vent their emotions and help them learn how to cope"

(Staff nurse, Omani, Hospital2)

All HCPs supported the integration of psychological support as part of standard care in fertility clinics. They believed in the positive effect of a patient's psychological status on their acceptance of fertility treatment. A few other HCPs mentioned their belief in better treatment outcomes among patients who are stable emotionally. A physician said;

"It's not easy for the ladies especially because once they are going through ovulation induction, they take tablets, they have to take injections, there is a particular timing. Infertility per se is a very stressful situation for the couple, for the women-emotional and physical discomforts are involved and I hope that they feel free to talk because even unburdening, telling somebody, maybe it's not easy to tell somebody at home but me being a third party who's not directly involved with their social circle, I think it helps psychologically ,I have a lot of patients who have said things about their social situation, the emotional stability is crucial for treatment acceptance and success"

(Specialist doctor, Indian, Hospital1)

Providing appropriate support (via another source i.e. a dedicated professional psychologist) was reported as the most appropriate way to provide emotional support to women, given the limited time during consultations for the treating physicians to do so. HCPs felt that such a service would should be within the fertility

clinic itself and it need to be labelled accordingly to ensure it is accepted by patients i.e. not seen as a stigma. In doing so, participants felt that patients would find it less stigmatizing and more appealing than having to attend a psychiatric department or hospital;

> *"I feel a lot of people will accept this, not like before. Because they need to go to talk to somebody, better than to go to psychiatric hospital, where there is a lot of stigma. The term "social worker" and inside the clinic will be better tolerated and will give them more time and support and will give them proper interventions on how to cope"*
>
> **(Specialist nurse, Omani, Hopsital1)**

It was also apparent from the interviews that HCPs felt women with PCOS experienced exceptional levels of emotional burden. A number of HCPs believed women with PCOS were more drained emotionally compared to other women with infertility (see Sub-theme3 Medical concerns specific for patients with PCOS, p246). HCPs believed women with PCOS should be prioritized in receiving emotional support given the extra medical challenges prevalent among them compared to other women without PCOS in fertility clinics. An Indian doctor shared her experience of 13 years in fertility clinics and encountering patients with PCOS;

> *"Emotionally they are different, because they have irregular cycles, so mostly from the adulthood itself, it has been a continuous process that they have been having irregular cycles, they have been on medications, even before they're trying for fertility, they have been to clinics for medications. They*

have acne, so they have that issue and they have hirsutism, so that is another major issue where they have to go frequently for removal of hair, or laser and that's something about the look itself. So, those issues, apart from infertility and some tend to be diabetic from a younger age. So they are definitely different. It does affect their emotions ... They are sometimes fed up, how often they will go for all these procedures, why it's not getting less and it's not disappearing and they cannot lose weight, so it's all a tug of war of emotions for them, so they are different and they are emotionally more challenged than the other infertility patients yes."

(Specialist doctor, Indian, Hospital1)

6.11 Theme 6:Challenges to providing a better level of fertility care

A considerable number of challenges were identified by HCPs that appeared to prevent them from providing optimal care to fertility patients (Appendix I6). Among the common challenges mentioned by HCPs regarding the clincs' settings was the unavailability of a private room in the clinic for men to provide seminal fluid when needed. HCPs reported that men find it inconvenient to be asked to use the hospital's public restrooms for this purpose and many fail or refuse to provide the sample which delays the treatment process.

"Some of them couldn't provide the specimen because they need a quiet place and privacy to feel assured and not watched over...some of them said that their husband couldn't provide the specimen and if she lives nearby I give her the specimen cup and wait around half an hour but if they live outside the city they rent a small flat to be closer to the hospital!."

(Staff nurse, Omani, Hopsital2)

Among the frequently mentioned shortcomings of the clinic's setup was the mix up of fertility patients with pregnant women in the waiting areas, which is believed to cause disturbance among patients seeking fertility treatment. A doctor mentioned this;

"They get frustrated because now they are waiting with the pregnant ladies here... Infertility clinic is not a different area, it's the same area and they come and sit with these pregnant women. Sometimes they have to wait for long time and this mix up is disturbing to them"

(Specialist doctor, Omani, Hospital2)

Finally, the ultimate challenge is the absence of IVF facility in these fertility centres, as it is considered as the last hope for many couples who cannot afford the expensive treatments in private clinics or abroad. A doctor talks about the frustration of coming to a dead end with their patients when IVF is required;

"They are frustrated that many cycles of ovulation induction are done, no pregnancy and they're coming to us with a new hope that there will be a pregnancy. The only option will be IVF and a major concern is that no IVF facility, in a government set up. So they have to manage their finances off their own, they have to look for the option. Mostly they cannot afford it and it's a dead end for both of us"

(Senior consultant, Omani, Hospital2)

6.12 Discussion

6.12.1 Summary of findings

Patients obtain access to these two fertility specialist tertiary hospitals through a referral system (that is countrywide), resulting in long waits for a first appointment due to the large numbers of patients attending. This high volume of patients was associated with challenges in delivering care among HCPS that included: short consultation times that often led to patients' dissatisfaction with the amount of information provided to them on the causes of their infertility and their low comprehension of the set management plan. HCPs reported patients attending these clinics had often sought fertility treatment elsewhere, mainly in private clinics due to reasons related to ease of access, privacy especially for husbands and the availability of more advanced treatment options specifically IVF which is not available in the government setting where they serve.

Different emotions were perceived by HCPs among these patients: while some were very hopeful to find a solution to their infertility, others were hopeless and sought treatment out of desperation to conceive. HCPs were able to perceive the different social and medical concerns affecting patients attending fertility clinics that had implications for their emotional stability. These included societal pressures to conceive and to seek medical treatment, and the emotional distress and anxiety experienced due to extensive fertility treatment. However a number of professional and social barriers were expressed by HCPs in approaching and addressing patients' emotions during medical consultations. The lack of continuity of care, limited time for consultations, a language barrier, a lack of proper training

to manage patients' emotional wellbeing and some patients' hesitancy to share emotions with professionals, due to social constraints, prevented HCPs from offering emotional support to their patients. It was noted that routinely checking on patients' emotional wellbeing is not a norm in clinical practice and HCPs who routinely checked did so through personal choice, rather than being part of standard care. Many HCPs tried to offer support through non-formal methods, such as optimizing the services offered in the clinic to these patients and through verbal and non-verbal communication with patients to show empathy. Direct support was usually only offered if HCPs were prompted by patients who either initiated the discussion or showed visible signs of distress. However, this support if needed was mainly given by physicians in the form of giving them more time to express their emotions and by using gentle words and phrases of encouragement. Many of the local HCPs also reported to refer to religion to console patients. The Omani nurses seemed to have a better rapport with fertility patients compared to physicians, as they spent a greater amount of time with them and met them more frequently during their visits. In addition, belonging to the same cultural background made them better understand patients' social concerns with infertility compared to expatriate nurses. These factors seemed to put them in a favourable position compared to physicians to offer education and counselling to fertility patients. However, the paradox was that physicians had a more dominant role compared to nurses during the consultation process. Physicians examine patients, conduct tests and procedures, explain and educate patients about their management plan, and thus enhancing nurses' role in providing support may be problematic in practice. Specialist nurses however were more involved in the clinic compared to staff

nurses, but these nurses were scant. Staff nurses who are greater in number had a very limited and marginal role in the clinic, and focused on guiding patients through the clinic and only assisted physicians.

There was a clear need to integrate emotional support as part of routine practice in fertility management. HCPs mentioned the social and medical pressures associated with infertility among Omani women warrants psychological support, especially for those with PCOS. Women with infertility and PCOS were thought to be more drained emotionally given the other common symptoms and comorbidities associated with their condition and being more challenging medically to respond to fertility treatment compared to other infertile women. Given the previously mentioned barriers among HCPs in addressing patients' emotional needs, emotional support was seen to be best offered by a professional psychologist, set within the fertility department, due to the stigma especially among patients associated with attending behavioural services.

6.12.2 Comparisons with other studies

Studies that have tried to understand HCPs' perceptions of the care provided to patients seeking fertility care are scant and have mainly focused on their evaluation of the provision of a patient-centred care approach, which included the element of emotional support (234, 241, 242). However no studies focused on understanding emotional support provision alone among patients and HCPs in the field of fertility. Most of the available studies have instead evaluated patients' experiences and satisfaction with the care received in fertility clinics using both quantitative and qualitative methods (217, 490-499) . However, it is considered equally important to

understand HCPs' perceptions of the care they provide to help compare it with that received by their patients to bridge any gaps in care, which is something this study has sought to do. The different aspects of fertility care as offered and perceived by HCPs in this study are discussed in turn below.

HCPs' views on aspects of communication with fertility patients

When the aspect of communication between HCPs and patients was discussed, many HCPs expressed how difficult it was for patients to comprehend the information exchanged during consultations. This finding was in line with their patients' experience (chapter 5), where many reported how difficult it was to understand the medical information related to their condition provided by physicians. HCPs related this to stress and anxiety levels experienced by fertility patients, as well as their level of education. However it was also noted that the majority of HCPs relied on verbal explanations and thus lacked the use of proper illustrative materials to help patients better visualise the problem causing their infertility or the clinical procedures they were about to go through, which have been shown to facilitate better understanding(500). A study with 240 women in the UK showed that patients did pay attention to how their doctor communicated with them, including the quality and the type of information provided, and women who could not grasp the information received from doctors resulted in them looking for other information sources which might not be accurate (54). Interviews with patients in this research revealed a similar experience, where patients had to rely on other sources of information such as; friends and the Internet, which have led to confusion and misperceptions. This emphasizes the need for HCPs to pay more

attention in providing information to fertility patients and to check their understanding.

Moreover, when patients' involvement in the treatment plan in this study was investigated, many HCPs reported patients as being passive receivers. HCPs related this to patients' trust in doctors' experience and therefore decisions. Other HCPs believed that patients strict and passive adherence to the set plan by them was out of their desperation to have a child regardless of the means or risks. In contrast these HCPs reported patients who were more educated, with longer duration of infertility and of older age were more vocal about discussing treatment options. However, HCPs might underestimated the importance of a patient's desire to receive medical information, as this perception was in contrast to findings from their patients' experience (chapter 5) and other studies reporting that fertility patients wish to be more involved in setting their treatment plan and to be given more explanation and alternatives for treatment options (415, 461, 501, 502). Furthermore, in a study exploring HCPs' perspectives of the quality of care offered in fertility clinics, HCPs underestimated the importance of providing information to their patients, where patients actually ranked this aspect of quality care highly (242). In spite of the perception among HCPs in this study that patients place more trust in physicians to make decisions related to their fertility management, nurses (Omani) in this study reported to have a better rapport with fertility patients compared to physicians. Nurses were seeing patients more frequently during their clinic visits and shared a similar cultural background. This perception among nurses was in line with their patients' actual experience (chapter 5), where patients reported to having a stronger bond with nurses compared to doctors for the same

reasons reported by these nurses. However results from this study also showed staff nurses as having a very limited role in fertility clinics compared with their specialist counterparts. Their focus was only on assisting physicians and guiding patients in the clinic to go through investigations and arranging their appointments, given the lack of proper training among them in this field. A similar finding was reported in a qualitative study in Kuwait that explored infertility patients' perceptions of the nurse's role during their treatment in IVF clinics (404), where most participants felt nurses only preformed their basic nursing role of checking and recording vital signs and preparing them for examinations (404) this was also consistent with the findings of another study(458). Several other studies in Western settings indicated fertility nurses to be important members within fertility healthcare teams (415, 458, 459, 503, 504) and they should be more involved in healthcare improvement initiatives (404, 460). Training fertility clinic nurses on providing patient with education, counselling and performing basic fertility procedures have also showed a positive impact on patients' satisfaction (458) (505). Implementing some training for nurses in fertility clinics in Oman taking into account the common cultural factors among fertility patients would be very useful to empower nurses to be more involved. This is supported by the fact that nurses are in a position to provide continuous patient care through frequent encounters and are able to establish a better rapport compared to physicians. Therefore providing the proper training to nurses would enable them to handle more core tasks in the clinic which would also serve to alleviate some of the pressures on doctors, which would further improve the patient experience.

Approaching and addressing patients' emotional wellbeing

To the best of the researcher's knowledge, this is the first study in the region to explore HCPs' perceptions of the care provided in fertility clinics, specifically the extent to which they approach and address patients' emotional wellbeing, using qualitative methods.

Results of this study revealed that HCPs in fertility centres are aware of the different social and medical stressors facing women attending their clinics, which were also expressed by their patients (chapter5). Despite this knowledge, HCPs mentioned being unable to give attention to patients' emotional wellbeing due to the existing constraints including limited consultation time, few staff, high volume of patients, lack of continuity of care and lack of training. These reasons were also reported by their patients when they were questioned about the possible reason behind the lack of emotional support by HCPs.

In contrast to HCPs' proper awareness of their limited role regarding provision of emotional support to their patients in this study, a large study by Aarts et al. found that Dutch HCPs overestimated their performance about the attention paid by them to the emotional impact of infertility when this was compared to their patients' perceptions(234). However in this study, the use of interviews instead of questionnaires helped HCPs' express their limited role in providing emotional support to their patients and further elaborate on the pertaining reasons behind it.

Most of the mentioned barriers to approach patients' emotions by HCPs in this study were more organisational rather than personal limitations. However, studies on professionals' perspectives of providing better care suggest there are more than

just organisational barriers in providing the care patients need. Fertility HCPs are more “provider focused” than “patient focused”(481); therefore they underestimate the importance of patient-centred care and focus more on outcome measures(506). In addition, it has been reported that HCPs normally lack the professional motivation to change (241), fail to translate feedback into solid measures(241) and they lack the experience to identify and meet patients’ needs(507, 508).

Furthermore, apart from the professional/institutional barriers mentioned above, HCPs in this study also highlighted their knowledge about the sociocultural constraint of approaching patients’ emotions, as they perceived that some women found it intrusive for HCPs to discuss their emotions, which they considered to be private. Sharing their feelings with HCPs was considered inappropriate during treatment of their medical problem. This was in line with findings from patients, where some were against being asked about their emotions by HCPs as they reported finding it inappropriate, within the context of seeking solutions for their medical infertility (chapter 5). Therefore some HCPs preferred not to touch upon patients’ emotions unless patients initiated the discussion themselves. Literature is lacking in the region to help understand the factors underpinning this behaviour among fertility patients; however evidence shows that people normally seek social support less in situations that threaten their self-esteem(509). Infertility might threaten self-esteem due to its stigmatizing nature as bearing a child is considered the norm socially and an inability to do so is considered a “deviant behaviour” therefore it could isolate couples from sources of support(510), particularly in Oman (and the Middle East) where bearing children is expected soon after

marriage. HCPs in this study revealed that some women attending fertility clinics feared to disclose information about their negative emotions from experiencing infertility, as they might be offered psychological support, which was also associated with perceptions of stigma as some people still believe attending a psychologist is a sign of severe mental illness, which in itself is socially stigmatizing. The stigma associated with expressing the need for psychological support or being referred for such support was also reported by patients in this research; suggesting these preconceptions are deeply embedded in the culture, across different groups and thus making recommendations or implementing such support requires careful thought. Therefore these women were under a lot of stress that was not only from experiencing infertility which was stigmatizing but also from trying to receive psychological support which was further impeded by the associated stigma socially. Therefore the need for emotional support among this group of women was evident, as HCPs believed many women would want to be offered such support. However, given the professional/institutional barriers and the presence of the wider cultural constraints, it is plausible to suggest emotional support to be best offered by a professional psychologist and within the fertility clinic to best suit the needs and the cultural boundaries of these women which is further discussed below.

HCPs' views on the need to provide emotional support to fertility patients

The HCPs in this study showed awareness of and the need for emotional support to be provided to their patients. However, the majority of patients in this study expressed their disappointment for their emotions not being attended to during the intensive treatment process, where the need seems to be greatest: especially when

treatments fail or when women experience a pregnancy loss (chapter 5). HCPs tried to provide this support in implicit ways such as by trying to facilitate the services offered to these patients in the clinic such as making appointments closer, helping them finish procedures faster and minimize the waiting time to see the physicians. Other HCPs provided support indirectly, through the use of empathetic verbal and non-verbal means of communication. A few HCPs referred to religion as a form of support by reminding patients that whatever happens is God's will and they should accept it. Words like "inshallah"- in the will of God, was frequently used to give patients hope. This form of support was also reported by a study in Kuwait about patients' experiences with support from nurses during fertility treatment(404). Studies report that infertile couples in the Islamic part of the world might be consoled when reminded about their destiny, as God wishes them to be childless and they should submit to his wish, which was also something the individuals themselves commonly referred to as a way to cope with their infertility, including women in this study (147, 404-406, 511). These religious and spiritual beliefs help women handle infertility peacefully by relying on a "higher being"(512). However, the results from this study showed that women still have emotional needs that ought to be addressed, given the amount of social pressure they experience, along with the burden of enduring fertility treatment. Especially that women in this research reported that this topic is not spoken about openly in the society due to the associated stigma, leaving these women isolated in the need to vent out the negative feelings (chapter 5).

Therefore, most of the HCPs that participated in this study supported integrating a psychologist-led support service as part of the routine care in fertility clinics.

Patients have also expressed their need for emotional support; this is supported by the positive impact experienced by those who did receive it from some of the HCPs (chapter 5). HCPs felt that this support would help to provide patients with the time and appropriate support required overcoming the existing barriers of emotional support provision by them. Suggestions for providing this service from within the fertility clinic and carefully labelling it would help to avoid the stigma associated from referring patients to psychiatry department/hospital, whilst ensuring women got the emotional support they need. Evidence shows that psychological interventions, such as cognitive behavioural therapy (CBT) (which is a form of psychotherapy that emphasizes the important role of thinking in how we feel and what we do) (513) and other techniques including relaxation techniques (514), expressive writing (515) and mindfulness (516) were found beneficial among infertile women; these studies also support the need for a professional psychologist within fertility clinics. However, the results from a study by Dancet et al. suggests that HCPs still need to provide a standard level of emotional support, especially because patients in this study reported that they expected to receive support from doctors and nurses during their daily care, by paying attention to emotional wellbeing and discussing emotional topics(414). Patients also appreciated receiving professional support from psychologists if further support was needed(414).The extent to which this is transferrable to Oman is however questionable given the limitations reported among fertility HCPs to offer this support and the negative views around seeking specialist behavioural support. Thus the suggestion of providing this support by a psychologist within the clinic along with the careful labelling of this service is believed to be the best way forward.

Evidence supports the importance of following a holistic approach in treating patients with infertility because the medical, psychological, spiritual and socio-cultural components of infertility are inseparable and need to be addressed (459, 460, 517). Evidence suggests that low attention to patients' emotions and lack of empathy of staff towards couples is a common reason for their dropout from fertility treatment(215). However, this was not observed among women in this research, as most adhered to treatment despite its extensive nature and lack of emotional support. This is believed to be due to these patients' desperation to have a child given the surrounding social pressure, treatment being offered free of cost and being fortunate to get access to country's highly reputable fertility centres (chapter 5). Perhaps the religious and cultural values and differences could account for these findings. Islam is a religion that places a high emphasis on fertility and marriage is linked to procreation(212). In addition, Oman is a country with a high fertility rate(250) and the use of family planning is still uncommon for the fear of infertility or for it to be against the teachings of Islam(518). This is further compounded by adoption to be socially an unacceptable solution for infertility (chapter 5).

Studies indicated that reduced psychological distress among couples during fertility treatment results in better fertility outcomes (462, 516, 519-522). Moreover, implementation of patient-centred approach was found not only to increase the satisfaction level among patients who receive it but also among HCPs who practise it(238).

HCPs in this study also believed that infertile women with PCOS need a greater amount of emotional support, given their slower response to fertility treatment and their higher risk of developing life-threatening complications from induction treatment. This is further supported given that many women with PCOS are also with high BMI (523) and struggle to reduce weight which further delays commencing fertility treatment and adds to their frustration. Women with PCOS and infertility in this research also shared this struggle of reducing excess weight and their frustration of having fertility treatment delayed as a result. They also complained about the lack of appropriate dietary/physical advice provided by dieticians to help them achieve this goal. In addition, the physical symptoms of the condition including excess facial and body hair, acne and loss of scalp hair is believed to add to their suffering by challenging their femininity from an early age (204, 524) which further warrants their need for emotional support.

The perceived gap in care at clinics' settings level

Findings from this study highlight aspects of care that require improvements. Among these is the absence of a private room in the clinic for men to provide seminal fluid, when needed for analysis or for IUI procedure. Absence of the privacy needed for men to provide seminal fluid in these clinics adds to the stigma associated with men attending fertility clinics and impede their willingness to cooperate in the investigations even if they wish to. In Oman It is uncommon for men to be seen attending fertility clinics, which are dedicated towards infertile women. Socially it is stigmatizing to relate pregnancy delay to men, and it is easier to blame women instead. Therefore, in this study men were reported by HCPs to be

less cooperative when they are asked to attend the clinic mainly due the associated stigma which is compounded by the lack of privacy. Similar attitudes among men were also reported by studies in other African and Asian countries when it comes to their role in fertility treatment (191, 305, 466, 525-527).

Furthermore, HCPs were able to perceive the distress among infertile women who have to sit side by side with pregnant women for a long time to see the physician during their appointments, as they both share the same waiting area and there is no separate area for women with infertility. This contradicts the patient findings, where some women preferred this set up as it helps maintain anonymity around their infertility visits. However, most patients interviewed in this study found it upsetting to see and hear pregnant women while they are struggling to conceive. Dancet et al. reported patients valued physical comfort during their fertility appointments, mainly to have waiting and consultation rooms to be exclusively for them without the need to mix with pregnant women as it was painful for them(414).

These issues around privacy in fertility clinics' set up were repeatedly experienced by HCPs and were also reported by their patients (see chapter 5, under: Gaps in clinic set up, p 196). Therefore, recommendations to provide a private room within the clinic for men to use to provide the seminal fluid and to give more privacy for infertile patients by separating their waiting area from those allocated for pregnant women should be considered.

The biggest challenge facing both HCPs and patients in fertility clinics in Oman as reported by them and many of the low resource countries, such as Egypt, India and

Thailand (where economic feasibility trials on IVF provision were carried out) is the lack of IVF services, which is considered a definitive standard in fertility management(528). Although patients in Oman are fortunate enough to receive fertility treatment for free without any cost, this treatment involves only first and second lines of fertility treatment where IUI is the highest level of fertility treatment offered. However many patients fail to conceive using these freely available techniques and financially cannot afford ARTs including IVF offered in private centres or abroad. HCPs described this as coming to a dead end with patients who are candidates for IVF treatment. Patients get very disappointed and frustrated finding that it is not provided nor financially supported as it was used to be in these tertiary hospitals which adds to their psychological strain.

The developed reproductive rights at the International Conference on Population and Development (ICPD) at Cairo supported the need to provide ARTs to overcome infertility to both men and women. In addition to the right of controlling fertility, the rights in reproductive health should include facilitating fertility when it cannot be achieved(529). Moreover the WHO considered infertility a global health problem and ARTs provision should be adapted in low-resources countries(530). Studies have been conducted in low resources countries such as Egypt, India and Thailand to try the use of a simplified version of IVF techniques due to resource limitations where it had modified some of the steps of the conventional IVF methods to cut down the cost without compromising effectiveness (531-536). Studies showed implementation of these techniques in low resource countries is feasible with similar success rates to the conventional methods (537, 538). Health economists in low resources countries including Oman might consider the cost-effectiveness of

providing these low cost techniques in governmental fertility clinics where advanced ARTs are very costly due to private monopoly(539).

6.12.3 Strengths and limitations

This study is the first in Oman and the Middle-east region conducted to assess the quality of fertility services from HCPs' perspectives, using qualitative methods. It has focused specifically on the extent to which HCPs approach and address patients' emotional needs within clinics.

This study adopted a purposive sampling strategy and involved 20 fertility healthcare providers comprising both physicians (gynaecologists) and nurses with different qualifications, years of experience, nationalities and who were from two different government fertility clinics in Oman. This approach allowed the researcher to capture a broad and diverse range of HCPs' experience with fertility patients, providing rich data(302), where data saturation was achieved(297). However non-participation of the only male physician available in practice at the time of the study did not allow the researcher to capture perceptions from the opposite gender in dealing with fertility patients in our culture; especially given that interviews with patients (chapter 5) reported their dissatisfaction encountering some of the male HCPs in fertility clinics. Despite this limitation, male physicians are rarely employed in fertility clinics in Oman due to cultural and religious restrictions. Therefore not exploring a male HCP experience might not have affected the validity nor the transferability of the study findings given the dominant female HCPs in the field who are a better representative of the current practice.

In addition, the use of a qualitative research design over the widely used standardized questionnaires and interviewing these participants face to face using a semi-structured approach was necessary. This method facilitated the attainment of a detailed account of HCPs' experiences of the daily care and contact with infertility patients and allowed the researcher to further clarify the discussions brought up by them(301). The rich data obtained through these methods is believed to be a more accurate means of understanding HCPs' accounts of the current fertility services and its challenges. Furthermore the researcher's use of reflexivity and bracketing during the research process (as discussed in chapter2), along with the selected methodology of data collection complied with the proposed guidance in enhancing data trustworthiness and thus credibility of the findings(290).

However, this study also has its limitations. Conducting the interviews with HCPs in only two of the highly specialized tertiary hospitals with advanced fertility facilities and highly qualified professionals might not fully represent the service available in other less specialized fertility clinics, and therefore might challenge the transferability of its findings to some of the less specialised units. However this study is the first in the country to assess fertility service provision and it undoubtedly has provided a valuable initial insight to help make recommendations for changes to be applied across them and across the other fertility clinics under the ministry of health that share the same standard of care if not less. Moreover, the recruitment approach relied on HCPs volunteering to take part, which might have introduced self-selection bias(540). This did not allow the researcher to explore the perceptions among the other HCPs who did not participate and who might have a

different experience. However, this is unlikely due to the good variety of participants that most likely compensated for this.

Finally, this study investigated HCPs' perceptions of care in fertility clinics to patients in general, regardless of the cause of infertility while the captured experiences of patients with fertility care was among infertile women with PCOS as the reason behind their infertility. This might affect the triangulation of findings from these two groups (see chapter 7). However, to overcome this, HCPs were specifically asked at the end of the interview about their experiences with women with PCOS which helped to capture their perception on this group of women.

6.12.4 Conclusion and recommendations

This study showed that HCPs working in fertility care in Oman are aware of the psychological burden experienced by their patients, due to societal pressures around bearing children soon after marriage and thus the subsequent stress and stigma associated with pregnancy delay and ensuing medical treatment. However, a number of organisational, professional and cultural barriers exist and prevent HCPs from approaching patients' emotions and providing much needed support. Despite this, HCPs felt there was a need for providing emotional support to this group of women, to help them accept and cope with their infertility both socially and medically. Support needs to be prioritized for infertile women with PCOS as they experience more psychological and physical suffering from disease related symptoms that are further compounded by their inability to conceive. This support was suggested as being best provided through a professional psychologist as part of

routine care, within fertility clinics to avoid the stigma associated culturally with seeking psychological support and thus help women better utilize the service.

Furthermore, this study showed the limited role of fertility nurses in fertility clinics despite their better rapport with fertility patients compared to physicians. Therefore, nurses in fertility clinics could be better trained to be able to provide more education and counselling. This role could also be extended to involve more hands-on nursing when it comes to procedures and medical tests in fertility clinics.

Results have also indicated that HCPs underestimate the importance of information provision and a patient's voice in discussing treatment options. This might be attributed to evidence-based medicine being more disease oriented and physician-centred rather than on patients' individual needs and preferences (541, 542). Therefore, residency specific training programs should start focusing on patient-centred care beside the heavily taught medical aspects of care.

Finally, HCPs identified a number of organisational related challenges that need to be tackled in order to step up with the level of care provided for patients in fertility clinics. The most important was the lack of ARTs namely IVF in government set up. In the profession of medicine as it is a patient's right to be treated to maintain their life it is also their right to be granted a life. It is time for health organizations to consider integrating these advanced fertility techniques as part of mainstream fertility care.

Future studies should provide more support to these findings and focus on synthesizing further evidence of the importance of applying patient-centred care including the provision of emotional support in fertility clinics. These studies should also be applied to other fields of medicine using both qualitative and quantitative methods on patients' and providers' perspectives to help recommend solid guidelines for its implementation as a standard of care. In addition, piloting behavioural support interventions in fertility settings will help assess patients' acceptance and utilization. This will further help to recommend whether this support is best offered by a specialist or by fertility HCPs.

Moreover, feasibility studies should be considered to evaluate incorporating ARTs in government hospitals in Oman to assess if it is economically a viable initiative.

7 General thesis conclusion and recommendations

7.1 Introduction

A literature gap was found around the available studies on PCOS in the Arabic world, specifically in the Middle East including Oman despite its disease comparable prevalence to that obtained from other countries worldwide(252). This research provided a valuable insight into the various reproductive effects of PCOS among Omani women. The first study examined the effect of the condition on selected metabolic, pregnancy and birth outcomes among affected pregnant women and their newborns. However, PCOS is also known as the most common cause of infertility among women in reproductive age(3), and many women succeed to carry a pregnancy after going through infertility and use of ARTs. Therefore, the second study sought to explore the psychosocial aspects of infertility due to PCOS among women in the context of living in the Omani society. The majority of these women will seek fertility treatment as it is accessible and available free of cost countrywide. However these women's experiences with fertility care services including the extent to which their emotional wellbeing is addressed and supported by fertility HCPs is not known and was further explored among these women. However, listening to patients' experiences, views and perceptions of the received care required a comparison to be made with HCPs' views and perceptions on these aspects to better bridge the gap in care. Therefore, HCPs' experiences of the offered fertility care including the extent of approaching and addressing patients' emotional wellbeing was crucial to be explored and was examined in a third study.

7.2 General conclusions

7.2.1 Quantitative study

The findings from the quantitative aspects of this research indicate women with PCOS are more likely to be diagnosed with selected metabolic outcomes during their pregnancy namely; gestational diabetes mellitus (GDM) and pregnancy induced hypertension (PIH) but not preeclampsia when compared to their counterparts. In addition these women are more likely to have a number of adverse pregnancy outcomes. Women with PCOS are at higher risk to have miscarriage of their pregnancy and to undergo preterm delivery before completing 37 weeks of gestation compared to controls. However they are at equal risk to their controls in the risk of having stillbirths. Women with PCOS are also at a significantly increased risk of delivery through emergency (unplanned) caesarean section compared to controls. On the other hand, these results provide an assuring evidence of newborns to mothers with PCOS not being at higher risk compared to newborns to mothers without PCOS in developing the following post-partum outcomes of macrosomia, low weight for gestational age, low APGAR score and admission to intensive neonatal unit. These metabolic, pregnancy, birth and neonatal findings are associated with PCOS and are not explained by women's characteristics including age, gravidity, use of ARTs or multiple gestations.

7.2.2 Qualitative studies

7.2.2.1 Psychosocial experience of infertility

Findings from this study revealed women with PCOS and infertility experience high psychological and social pressures to conceive as a result of living in the Omani society. Culturally pregnancy is expected right after marriage and it is the only legitimate way for men to prove their fertility. Women are most often blamed for infertility as it is unacceptable socially for men to be labelled “infertile”. Therefore, women are exposed to a tremendous amount of social pressure especially from their in laws due to their inability to conceive. Women are facing different forms of harassments from in laws in the form of continuous questioning about their pregnancy delay, constant comparisons with other fertile couples and being treated inferiorly. They also continuously pressurize their sons to remarry for a child as having children is considered of high value in Omani society and religiously marriage is the only legitimate way for family formation.

As a result, women revealed having mixed emotions going through the experience of infertility coupled with the existing social pressure. These include feelings of sadness and sorrow, inferior to other fertile women, jealousy towards women with children and feelings of guilt being the reason of infertility and unable to grant their husbands a child. The majority of women revealed their preference not to share their negative feelings with people in their social circle due to feelings of being inferior and vulnerable around them. This is believed to keep them away and

isolated from sources of support and thus negatively affects their emotional stability further, making them in greater need of a professional emotional support.

Living in an Islamic and religious community, women use their spirituality and religious practises as ways to be consoled about being childless. Their use of faith and hope in God gave these women hope that their prayers would be answered and that they would be granted children one day. Women also used different coping strategies to live with their infertility including; self-distraction by taking up different activities and social adjustments mainly in the form of social isolation and moving out of their in law's house. Although the long duration of infertility helped coping with infertility get easier, it was found to be the source of marital tensions. This was found to be due to the constant prolonged social pressure on men to bear children, and also appears to be due to the emotional gap apparent between couples as each one tries to be distracted and stay away from the other as a coping mechanism.

Adoption is socially rejected in Oman and there are generally negative views around it. This was mainly found to be due to common beliefs of adoption being forbidden in Islam and the belief of adopted children to be fondling children and have originated from sinful relationships, therefore abandoned by their biological parents. However Islam is a flexible religion and adoption is permitted under certain conditions but unfortunately most people are not aware of this as it is a sensitive subject culturally and is rarely spoken about publicly. These deeply embedded cultural beliefs against adoption were the reasons of many of these women to hesitate in taking this step, despite their willingness to do so given their

instinctive nature to experience motherhood. The cultural unacceptance of adoption as a solution for a couple's infertility (unlike it among the Western nations) is an additional burden on Omani women with infertility that threatens the continuity of a couple's relationship, especially if women were the reason behind infertility.

This negative experience with infertility socially and due to these women's belief of the medical causes compared to the super factious societal beliefs behind their infertility, made them seek fertility treatment early to assist them conceive.

7.2.2.2 Experience with emotional support during consultation from patients' and healthcare providers' views

Triangulating the findings from patients' and HCPs' interviews on the fertility services received and offered respectively showed that generally fertility HCPs in Oman are in line with their patients' actual experience, specifically regarding the provision of emotional support. HCPs were able to perceive the social and medical concerns among their patients as they were expressed by them. HCPs were aware of patients' desperation to have a child partially due to the experienced social pressure on them due to their childlessness. In addition, since the majority of the women have been exposed to fertility treatment in private settings prior to their access to government clinics, many of the HCPs were also aware of their frustrations relating to having long waits to be seen and to get their investigations completed.

However HCPs were honest to admit the lack of approaching and offering the support needed for the similar reasons expected by their patients when interviewed, which were; the lack of time due to high patients volume, the language barrier, the focus and the training to treat the medical causes and the resentments of some patients to share their emotions due to social constraints. Despite that a few patients preferred not to be asked about their emotional wellbeing, the need for emotional support among these women was evident. Especially at times of pregnancy loss or breaking of bad news about their treatment such as their need for IVF as it is not available in these settings. This suggests that emotional support should be subjectively assessed and tailored according to patients' needs.

The form of support offered by HCPs was mainly indirect through the use of gentle words and non-verbal communication methods that showed empathy. It was also through facilitating these patients' journeys, such as trying to ensure that there was not too much time between follow up appointments or fast tracking investigations. In addition many of the local HCPs used religious beliefs and phrases as a way to console patients about their destiny as they share the same religious background to that of their patients. However this form of support although was believed by HCPs to have helped patients emotionally, it was not appreciated by the women attending these clinics, as the majority disappointedly expressed a lack of any form of support. This shows that there is a disconnect between the two groups' expectations and patients' need being unmet, hence suggesting to use these findings in HCPs' training courses and as an evidence for investing in psychological resources to provide this support.

On the other hand a few HCPs were continuously inquiring and offering emotional support to their patients as a personal choice rather than as a standard of care. This was reflected in patient interviews, where only a few women named a number of HCPs who used to provide emotional support and expressed that it was part of their personal character. It was also noted that the use of a holistic approach including providing emotional support towards fertility patients was more practised among senior and thus experienced fertility HCPs compared to junior HCPs who focused more on the medical aspects of the condition.

In addition, both patients and HCPs believed in the potential role nurses could play in fertility clinics, in counselling and educating patients compared to their current marginal role. Nurses' extended involvement is justified by the continuity of care provided by them compared to physicians where they are in a better position to establish rapport with patients. This is especially important as many patients find it difficult to comprehend information related to their management from physicians due to short consultation time, language barrier and lack of both continuity of care and illustrative materials. However findings from HCPs' interviews related patients' low comprehension and lack of involvement in setting the treatment plan to their educational level and their prior experience with fertility treatment. This suggests that HCPs' underestimate the importance of information provision to fertility patients as their perception on this aspect of care mismatched that from their patients who expressed their willingness to be more involved in their treatment plan rather than to be treated passively.

Both patients and HCPs expressed the need for emotional support to be integrated as a routine standard of care and as part of fertility treatment, to help patients better cope with the social strain of infertility and better accept the physical and psychological burden of fertility treatment. Given the perceived social stigma associated with seeking help for emotional wellbeing and to overcome the current professional/institutional barriers for this support to be provided by fertility HCPs. Both HCPs and patients agreed that this support was best provided by a professional personnel (psychologist), within the fertility clinics and should be carefully labelled.

Although providing emotional support by a professional psychologist seems important, patients might also expect a standard level of support to be offered by their fertility HCPs, given the positive experience reported among those who have received it, and because patients will see these individuals regularly during their fertility treatment.

Moreover, this study involved women with PCOS being the reason behind their infertility. Both patients and HCPs perceived having PCOS to be more challenging medically and emotionally, particularly due to the common associated issues of increased weight and the other existing comorbidities that might remain or occur even after conceiving that challenge their pregnancy as these were also identified in the quantitative aspects of this research. This makes it plausible to suggest that women with PCOS who are infertile or conceive through fertility clinics are more drained emotionally and are in a greater need for both emotional and physical support during the treatment process. Especially that many women expressed their

struggle to lose weight as a mandatory step prior to the commencement of fertility treatment given the lack of experienced dieticians to help them achieve this goal. Therefore support to this group of women might be best achieved through a multi-disciplinary team of fertility and reproductive HCPs, endocrinologists, dieticians and psychologists.

However willingness to take up these services especially regarding the emotional support services and the availability of the required resources in these institutions to implement these recommendations are not clear and further evaluation studies are needed to investigate the level of support needed and how the various parties could be involved. This could lead to piloting an approach and then taking it from there to revise and set guidelines to implement a more holistic approach for managing patients with PCOS and providing them with the needed support physically and emotionally.

7.2.2.3 Experience of exposure to fertility health care service

Findings from this research revealed that many couples in Oman prefer to start fertility treatment in private or abroad due to quick access, privacy and the belief that these centres have better experts and treatment options compared to government fertility clinics. This exerts financial burden on couples seeking fertility treatment and therefore they shift to government clinics after depleting their savings. HCPs were aware of patients' journeys with fertility treatment in private prior to receiving them in their government settings. Therefore they were able to understand their frustration with the long waiting time to get their appointments

and to complete their investigations due to the high volume of patients in these fertility centres. Therefore some sort of support or acknowledgment early on by fertility HCPs themselves could play a role in alleviating this frustration.

In addition, HCPs attributed the stress and sense of urgency to get treatment started among these women to the social pressures from their in laws, who were likely to pressurize their sons to remarry for children. This perception of a woman's emotional status was more often appreciated by the Omani HCPs belonging to the same cultural background compared to their expatriate counterpart. This reflects that local HCPs are in line with infertile patients' social and cultural circumstances. However spreading awareness about the common cultural attitudes toward infertility should be considered among expatriate HCPs to help them better support this group of women attending these clinics.

When the general environment and setting of the included fertility centres were evaluated, it was apparent that these centres were dominated by women. Men were unlikely to attend fertility consultations unless they were willing to or asked to by HCPs. This further emphasizes the cultural attitude of women to be blamed for infertility and that this setup almost helps to protect a man's image in the society of not having any fertility issues and thus is dominant. This female dominating environment is not inviting for men to contribute in the treatment process even if some are willing to.

However, the caveat is that there is no private room for men to provide semen fluid needed for tests and insemination procedures, which women found disturbing. HCPs were aware of the difficulty faced by women due to this issue and its role in

delaying the treatment process further. This was attributed by HCPs to limited resources in terms of limitations in the number of rooms available in the clinic, given the clinic is also shared by obstetrics physicians who follow pregnant women coming for antenatal visits. Therefore fertility clinics should consider allowing men to freely attend the consultations. Furthermore providing the needed privacy for men in the clinics and the required physical comfort will be the first step to make these clinics more inviting for them. This will help men to better support their partners and this would help change the social belief of infertility to be always attributable to women. It will also contribute to trying to destigmatize infertility in general and will help spread the idea that both men and women are involved in this issue.

Consequently the shared waiting area in the clinic between infertility patients and pregnant women was a source of physical and emotional disturbance to many women with infertility and it was also perceived by the HCPs. It exacerbated the feelings of sadness among these women as they were trying hard and were desperate to conceive yet they were surrounded by pregnant women. However since some of the interviewed women shared their preference to hide their infertility issue, this mixing would serve this purpose and seemed beneficial to them as for them it serves to perpetuate the broader cultural matters surrounding infertility. Change in the current setting by separating fertility clinics from antenatal clinics will help towards the steps needed to be considered in destigmatizing infertility and for it to be considered as any other medical condition that has its own dedicated clinic.

Moreover both women and HCPs find the unavailability of advanced assisted reproductive techniques in the government settings in Oman namely IVF as a huge obstacle and a challenge for those who needed it and could not afford it in private. This was found to be an additional emotional burden on infertility patients and negatively affects the job satisfaction among fertility HCPs.

7.3 Reflexion on researcher's positionality at the end of interview conduction

Despite belonging to the same cultural background of that of the interviewed women, the research findings emphasised some social differences and proved wrong some of the preconceptions among interviewed women acquired from anecdotal evidence. For instance, it was interesting for the researcher to learn about womens' thoughts around adoption, especially that a number of them did not know about its existence while others had a strong belief of it to be forbidden in Islam. Being a researcher from the same culture and sharing the same religion to that of the interviewed women, the researcher felt the obligation and the need to clarify these issues around adoption and that it is permitted in Islam. This was done at the end of the interviews after stopping the recordings, where the researcher had the opportunity to make women aware about the possibility to adopt in the sense of raising the children at their homes. Most of the women were only familiar with the financial adoption methods, in which they only financially sponsor a child who is in the orphanage. Moreover she clarified the common misconception around adoption in being forbidden in the religion of Islam by explaining the conditions that allow it by Islamic scholars. She has also shared the story of a relative who is currently an advocate for adoption in Oman through her

participations in different public platforms including the media to share her journey and experience with adoption.

7.4 Implications for practice

In short, this thesis would help HCPs in practice to clearly follow the reproductive health journey of women with PCOS living in the Omani society. Women with PCOS in Oman start to suffer from an early age. They normally get diagnosed early around puberty due to menstrual irregularities. Mothers of these young girls perceive menstrual irregularities alarming as it is a sign that threatens their fertility in the future and thus rush them to be diagnosed. They get physically and emotionally affected by the male like symptoms associated with the condition, as they threaten their femininity and self-esteem. After marriage many of these women will struggle to carry a pregnancy leading to subfertility and infertility. Infertile women with PCOS experience tremendous amount of social pressure to conceive. This pressure is sourced to the high social value placed on fertility in the Omani society and adoption being an unacceptable solution for infertility. Therefore, women will start seeking fertility treatment soon after marriage to escape the lived social rejection and to protect their marriage. However, they get disappointed not to have their emotions attended to by HCPs despite the experienced societal pressures and the medical burden of going through the extensive fertility treatment. On the other hand, HCPs are aware of their patients' need for emotional support but this support cannot be addressed given the existing professional, institutional and social barriers. Subsequently, women who succeed in carrying a pregnancy going through ARTs in these fertility clinics are still challenged

by the high risk of developing various metabolic, pregnancy and birth adverse outcomes which continue to jeopardize their physical and emotional health. Therefore, the insight provided by this research warrants prioritizing support to women with PCOS both physically and emotionally throughout their journey with medical services.

Moreover infertility and adoption is still considered as taboo and as topics that are stigmatizing socially. Evidence suggests that social behaviours are supported by a matrix of norms, beliefs, and schemas, and to transform behaviours a new positive norm should be created(543). Since evidence is lacking regarding the interventions used to change negative social attitudes towards infertility and adoption, an example was found in the literature to change the cultural norms towards violence against women in African countries(543). These could be applicable, and an initial first step towards normalizing and destigmatizing infertility and adoption in the Omani community. The first step is through community engagement and this is facilitated by identifying key informants, community discussions and interventions and community leaders to promote against stigmatization of infertility and adoption. It is also essential to involve stakeholders from the beginning to help design, implement and evaluate interventional programs. A good example of this was the project that aimed to generate new insights about the views, needs and experiences regarding infertility and fertility care and to increase knowledge and awareness about infertility and create possible interventions among relevant stakeholders and institutions in Kenya and Ghana(544). The project comprised multi-methods studies in Ghana and Kenya as well as dissemination workshops and meetings in these countries and the Netherlands(544). It was community based and

involved researchers from different fields that involved public health researchers, students, NGOs, support groups, stakeholders, private fertility clinics and officials from ministry of health(544).

The second step is to make it public and stop hiding the issue of concern. Therefore findings from this research should be disseminated to different platforms locally including schools, medical schools, residency programs, medical institutions at their different levels and the different forms of media. This would help in getting these women's voices heard and for a more modernised view towards infertility and adoption to take place in Oman. In addition, changes in fertility clinics' settings by dedicating special clinics exclusively for infertility couples and making them more equipped and inviting for men to attend falls within breaking the silence and normalizing infertility; as such negative practices reinforce the negative social attitude towards infertility. Therefore the first recommendation from the project mentioned above in Ghana and Kenya was that tackling stigmatization of infertility is a major issue to counteract the negative images and reactions towards infertile women and men. This was thought to be best achieved through the public 'coming out' of infertile people to correct the common widespread misconceptions around it.

The third step is to involve religion, especially in communities where it shapes cultures and social, political, and economic lives and is a powerful force influencing social norms as it is the case in the Omani community. Social norms and religious beliefs are intertwined and when social norms and religious traditions and practices come together, they significantly affect individual attitudes towards a certain

phenomenon. For instance there is a common misconception about adoption to be forbidden in the Islamic religion and because the topic of infertility is not spoken about publicly there is less awareness among people about the teachings of Islam around the notion of adoption. If Islamic scholars are given the platforms to address more openly the topic of infertility and adoption and clear the wide misconceptions then that would help significantly to end the negative attitudes in the society towards these issues due to religion's large role in influencing people's everyday life. The use of community based interventions and approaches are also proved beneficial through individual level (using peer support, role modelling, and action through advocacy) and the systems level (policy, services, institutions). Finally public health initiatives should partnership with researchers to optimize support programs that spread awareness and help in their implementation and evaluation.

7.5 General recommendations and future research

This research has examined the effects of PCOS on the reproductive health of Omani women. It has evaluated the health consequences of PCOS on pregnant women and their newborns and it extended this to explore the psychosocial experience of women with PCOS and infertility in the context of living in the Omani society. Furthermore, it has mapped both patients' and HCPs' views on the current services provided in fertility clinics, specifically on the provision of emotional support which is believed to have provided a better evaluation of the service on this aspect. Therefore, the findings from this research provide evidence for the following recommendations to be suggested in order to provide a better quality of reproductive care to women with PCOS:

- Women with PCOS should receive vigilant surveillance during pregnancy to monitor their metabolic vitals, namely their blood sugar levels and their blood pressure readings to detect outcomes of gestational diabetes and pregnancy induced hypertension in a timely manner. These metabolic outcomes might have more serious consequences for both mothers and their newborns and may turn into lifelong morbidities among these women (145, 265-267).

- Pregnancies among women with PCOS should be considered as precious pregnancies and thus should be closely monitored for the risk of miscarriage, preterm delivery and the risk of undergoing emergency

caesarean section as mode of delivery. These outcomes carry additional health risks to both mothers and their newborns (366, 367).

- Newborns to mothers with PCOS are found to be at an equal risk to newborns to mothers without PCOS in their birth weight, vitality after birth and in the likelihood to be admitted to NICU after birth. However close monitoring should be offered to these foetuses as they are still at higher risk to be born before term and thus are still hypothetically exposed to the risks associated with prematurity.

- Findings from the qualitative studies support the importance of providing emotional support in fertility clinics in Oman to women, given the experienced social and medical burden attributable to infertility and its treatment. This support is best offered by a professional psychologist within the fertility clinics. Careful labelling of this service is needed to avoid the social stigma associated with these services and help women better accept and utilize the offered support.

- Nurses in fertility clinics should receive proper training to have an educational and counselling role and learn basic fertility skills and procedures. This extended role of fertility nurses would allow patients to be better supported efficiently and empathetically.

- Residency programs for fertility physicians should include emotional support classes and workshops in their curriculum along the heavily taught medical

aspects of care in order to help doctors master the required skills to offer the much needed emotional support in the field of fertility care.

The voice of Omani women with infertility at the background of the experienced social pressure and the negative attitude towards adoption should reach out to different professional and social groups to help destigmatize these issues and thus better support women with infertility. This could be achieved through presenting study findings to medical journals, policy makers, health centres and organisations, medical students and residency programs and get the public exposed to it through the different forms of media.

- Change should be considered in providing more privacy for men in fertility clinics in Oman to help them get more involved in the treatment process. In addition fertility clinics should be less restricted and make clinics' environment more inviting for men to attend the consultations and thus facilitate their support to their partners throughout their treatment journey. This would also help reduce the stigma and the social perception of women to be always the reason behind infertility.

Community based initiatives should be considered that involve volunteers from different sectors to partner with public health researchers to generate programs and interventions that aim to better support infertile women and destigmatize infertility and adoption taking into account the cultural and religious background of Oman.

Future research should consider prospective data collection in larger cohorts of pregnant women with PCOS and their newborns to strengthen the evidence of the quantitative findings in this study. More outcomes should be examined and more residual confounders should be carefully accounted for in the analysis. Participants' BMI should also be involved and carefully accounted for. The effect of high BMI on the various outcomes among women with PCOS should be better analysed to be able to understand whether it is a factor on the pathway to these outcomes or has a compounding effect once it is present. Moreover, countrywide prevalence of PCOS is still unknown and thus it is worth being enumerated.

This study was the first to explore the psychosocial experience of infertility among Omani women using qualitative method and this was among women with PCOS. It is worth exploring the experience of infertility among other groups such as due to other causes or those with male factor infertility. Moreover, continued research is needed on PCOS due to its wide nature including exploring the psychosocial effects of PCOS diagnosis itself including the accompanying male like body symptoms among these women in the Omani society.

Evaluation studies should be considered to assess women's utilization of emotional support services within fertility clinics, given the associated stigma socially. In

addition studies on the cost effectiveness of incorporating ARTs namely IVF in government settings is worth consideration given the existing high demand by both patients and HCPs.

8 Appendices

Appendix A: Abstracts accepted for poster presentations in the 3rd International conference in Advances in Obstetrics and Gynaecology (ICAOG)-Muscat/Oman (21st-22nd /February/2019)

Appendix A1: Poster (1): Association between polycystic ovarian syndrome (PCOS) and adverse pregnancy and birth outcomes in Omani women

Association between polycystic ovarian syndrome (PCOS) and adverse pregnancy and birth outcomes in Omani women

Dr.H.H.ALSumri *, Dr.L.Szatkowski, Dr.J.Gibson, Dr.L.Fiaschi,Dr.M.Bains, Division of Epidemiology and Public health, School of Medicine, University of Nottingham, UK.
*Department of Family Medicine and Public Health, College of Medicine, Sultan Qaboos University, Oman

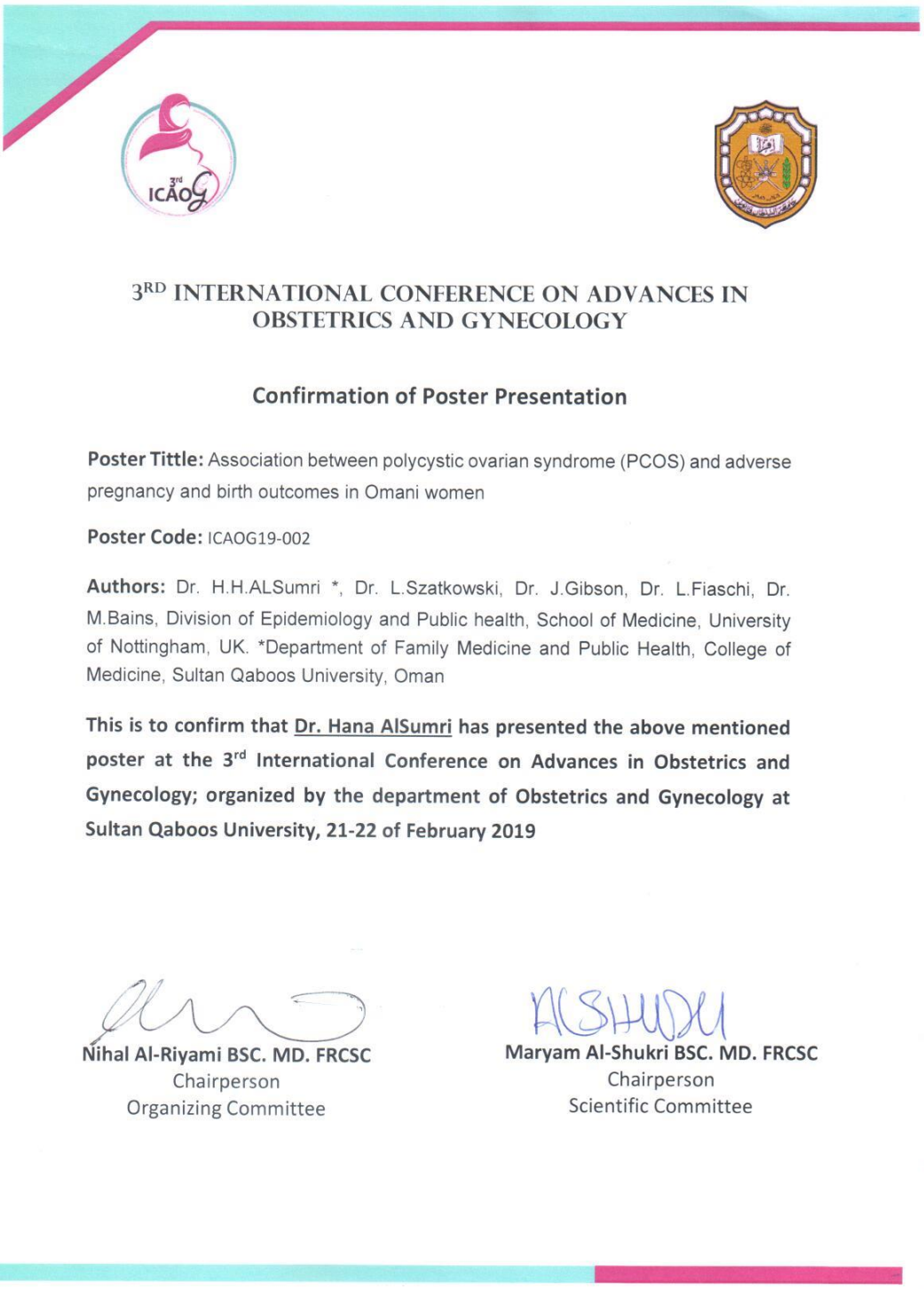
Objectives: To examine the association between polycystic ovarian syndrome (PCOS) and selected metabolic and adverse birth outcomes among pregnant women in Oman.

Materials and methods: This is a retrospective cohort study**.** Electronic hospital records from two tertiary hospitals in the capital city Muscat were used to collect data on a total of 1,939 pregnancies among 305 women with a diagnosis of PCOS (according to the Rotterdam criteria) and a control group of 617 women without PCOS recorded between 1st January 2006 and 31st May 2017. Multivariable multilevel regression models were employed to compare pregnancy and birth outcomes between women with and without PCOS, adjusting for confounding and clustering effects.

Results: Women with PCOS were more likely to develop adverse metabolic outcomes during pregnancy compared to women without PCOS (odds ratio (OR) for gestational diabetes (GDM) =2.56, 95% CI 1.44-4.54; OR for pregnancy induced hypertension (PIH) =2.53, 95% CI 1.02-6.28). The odds ratios for miscarriage and pre-term delivery were also higher in pregnancies where the mother had PCOS (OR=3.41(95% CI 2.23–5.22, p<0.001) & (OR=3.00, 95% CI 1.55-5.85), respectively), as was the odds ratio for undergoing emergency caesarean section (OR=3.47, 95% CI 1.55-7.78).

Conclusion: Pregnant women in Oman affected by PCOS are at a significantly increased risk of GDM, PIH, miscarriage, preterm delivery and undergoing

emergency caesarean section. Close antenatal monitoring is vital for early detection and control of metabolic disorders in women with PCOS and will help timely intervention during delivery for better mother-foetal prognosis.



3RD INTERNATIONAL CONFERENCE ON ADVANCES IN OBSTETRICS AND GYNECOLOGY

Confirmation of Poster Presentation

Poster Tittle: Association between polycystic ovarian syndrome (PCOS) and adverse pregnancy and birth outcomes in Omani women

Poster Code: ICAOG19-002

Authors: Dr. H.H.ALSumri *, Dr. L.Szatkowski, Dr. J.Gibson, Dr. L.Fiaschi, Dr. M.Bains, Division of Epidemiology and Public health, School of Medicine, University of Nottingham, UK. *Department of Family Medicine and Public Health, College of Medicine, Sultan Qaboos University, Oman

This is to confirm that Dr. Hana AlSumri has presented the above mentioned poster at the 3rd International Conference on Advances in Obstetrics and Gynecology; organized by the department of Obstetrics and Gynecology at Sultan Qaboos University, 21-22 of February 2019

Nihal Al-Riyami BSC. MD. FRCSC
Chairperson
Organizing Committee

Maryam Al-Shukri BSC. MD. FRCSC
Chairperson
Scientific Committee

Appendix A2: Poster (2): Psychosocial impacts of infertility among Omani women with polycystic ovarian syndrome (PCOS)

Psychosocial impacts of infertility among Omani women with polycystic ovarian syndrome (PCOS)

ALSumri,H* *Gibson, J., Fiaschi, L., Sztakowski, L., M,Bains.,* Division of Epidemiology and Public Health, School of Medicine, University of Nottingham, UK. *Department of Family Medicine and Public Health, College of Medicine, Sultan Qaboos University, Oman

Objective: To understand the psychosocial experience of infertility among women with polycystic ovarian syndrome (PCOS) in Oman.

Methods: Semi-structured interviews were conducted with 20 Omani women diagnosed with PCOS and infertility across two fertility clinics, in Muscat. Interviews were audio-recorded, transcribed verbatim and analysed using the framework approach.

Results: Culturally, women are expected to conceive soon after marriage and most participants felt they were blamed for any delay. Participants revealed experiencing psychological and social pressure to bear children, mainly from their in laws. Women reported constantly being compared to other women, and that families even suggested their husbands remarried. The majority of women mentioned being emotionally supported by their partners, however marital tensions were apparent in couples that had been experiencing infertility for longer. Women also shared feelings of loneliness, jealousy and being inferior to other women, disappointment from fertility treatment failure, and a fear of not having children to look after them in older age. Whilst women who had been infertile for longer seemed to be coping better, participants were using different strategies to cope with infertility. These included occupying themselves by taking up activities, avoiding social gatherings and moving out from their in laws' house.

Conclusion: Omani women with PCOS and infertility experience significant psychosocial challenges particularly in terms of feeling accepted by society, given the high value placed on fertility within the culture. After gaining insight into these psychosocial experiences of women with infertility, health care providers should consider offering emotional support during medical consultation to this group of women.

3RD INTERNATIONAL CONFERENCE ON ADVANCES IN OBSTETRICS AND GYNECOLOGY

Confirmation of Poster Presentation

Poster Tittle: Psychosocial impacts of infertility among Omani women with polycystic ovarian syndrome (PCOS)

Poster Code: ICAOG19-003

Authors: ALSumri, H* Gibson, J., Fiaschi, L., Sztakowski, L., M,Bains., Division of Epidemiology and Public Health, School of Medicine, University of Nottingham, UK. *Department of Family Medicine and Public Health, College of Medicine, Sultan Qaboos University, Oman

This is to confirm that Dr. Hana AlSumri has presented the above mentioned poster at the 3rd International Conference on Advances in Obstetrics and Gynecology; organized by the department of Obstetrics and Gynecology at Sultan Qaboos University, 21-22 of February 2019

Nihal Al-Riyami BSC. MD. FRCSC
Chairperson
Organizing Committee

Maryam Al-Shukri BSC. MD. FRCSC
Chairperson
Scientific Committee

Appendix A3: Conference attendance Certificate



Certificate of Attendance

This is to certify that

Dr. HANA ALSUMRI

has attended the
3rd International Conference
On Advances in Obstetrics and Gynecology

at Crowne Plaza Muscat OCEC on
21st – 22nd February 2019.
This activity has been accredited for
11.5 CME points in Category 1, OMSB/CPD/C1/1554/2019

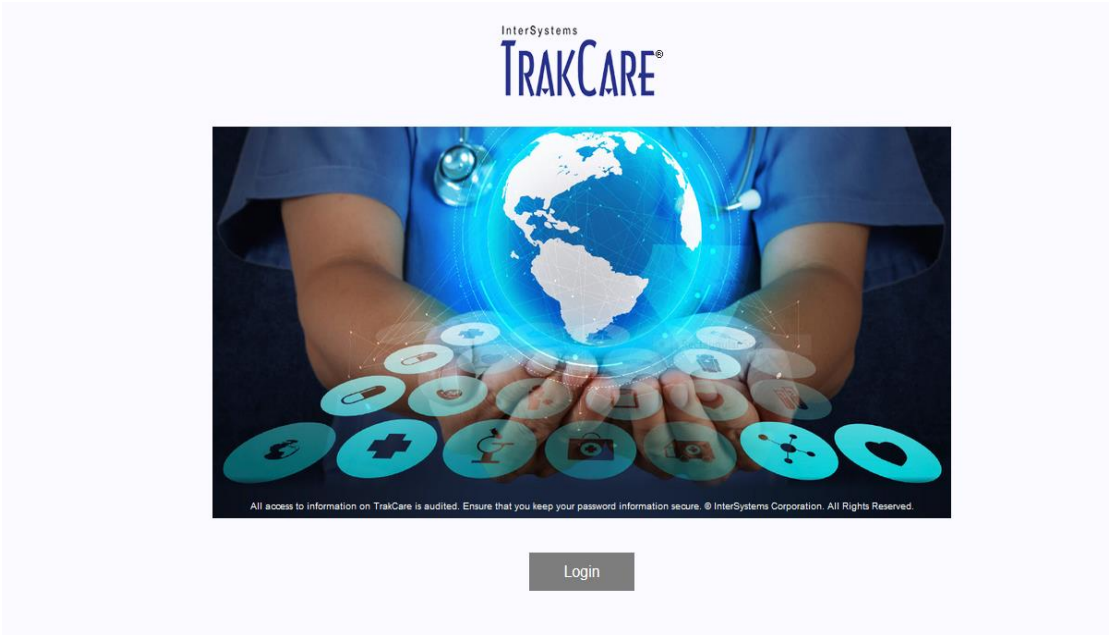
Dr Nihal Al Riyami
Chair
Organizing Committee

Dr Muna Al Saadoon
Dean
College of Medicine & Health Sciences

Appendix B: Ethical approvals

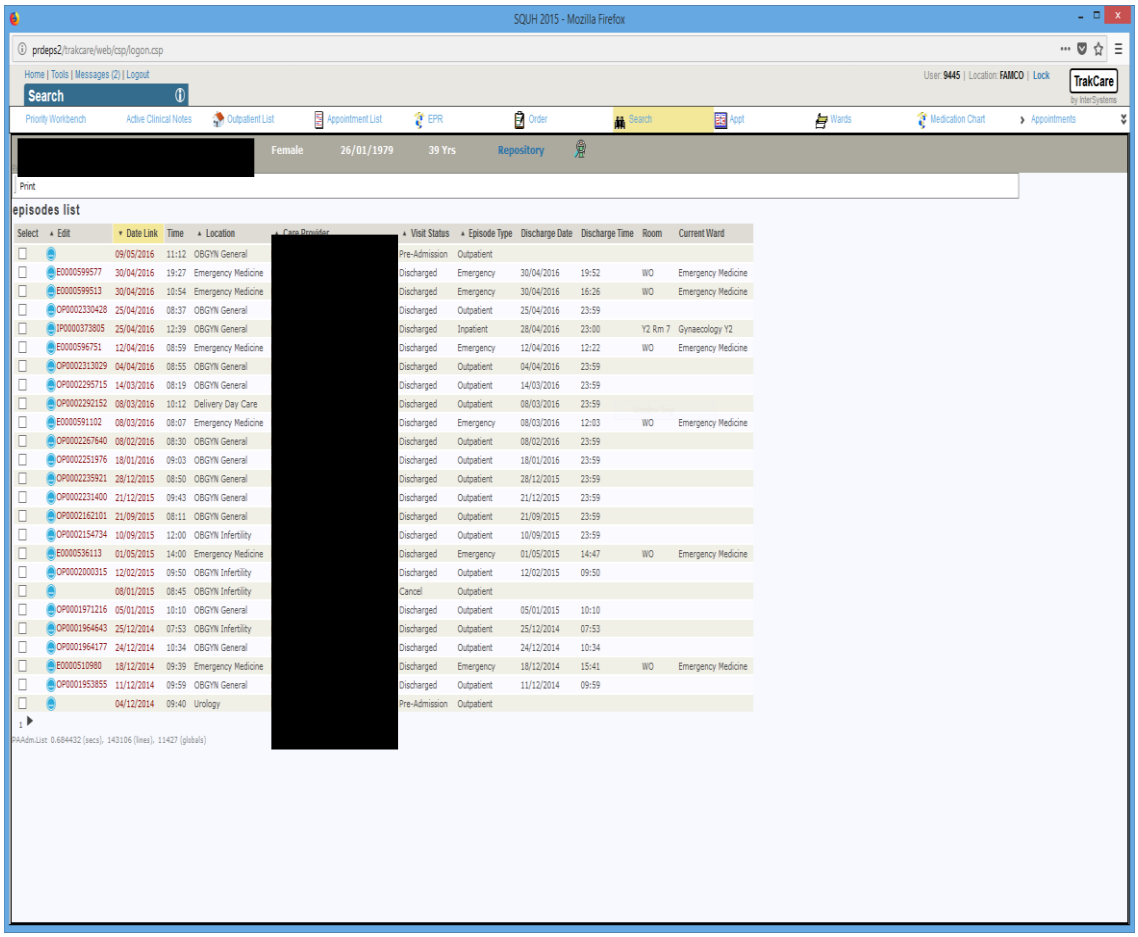
Appendix B 1: Sultan Qaboos University health information system (TrakCare)

1-The log in page



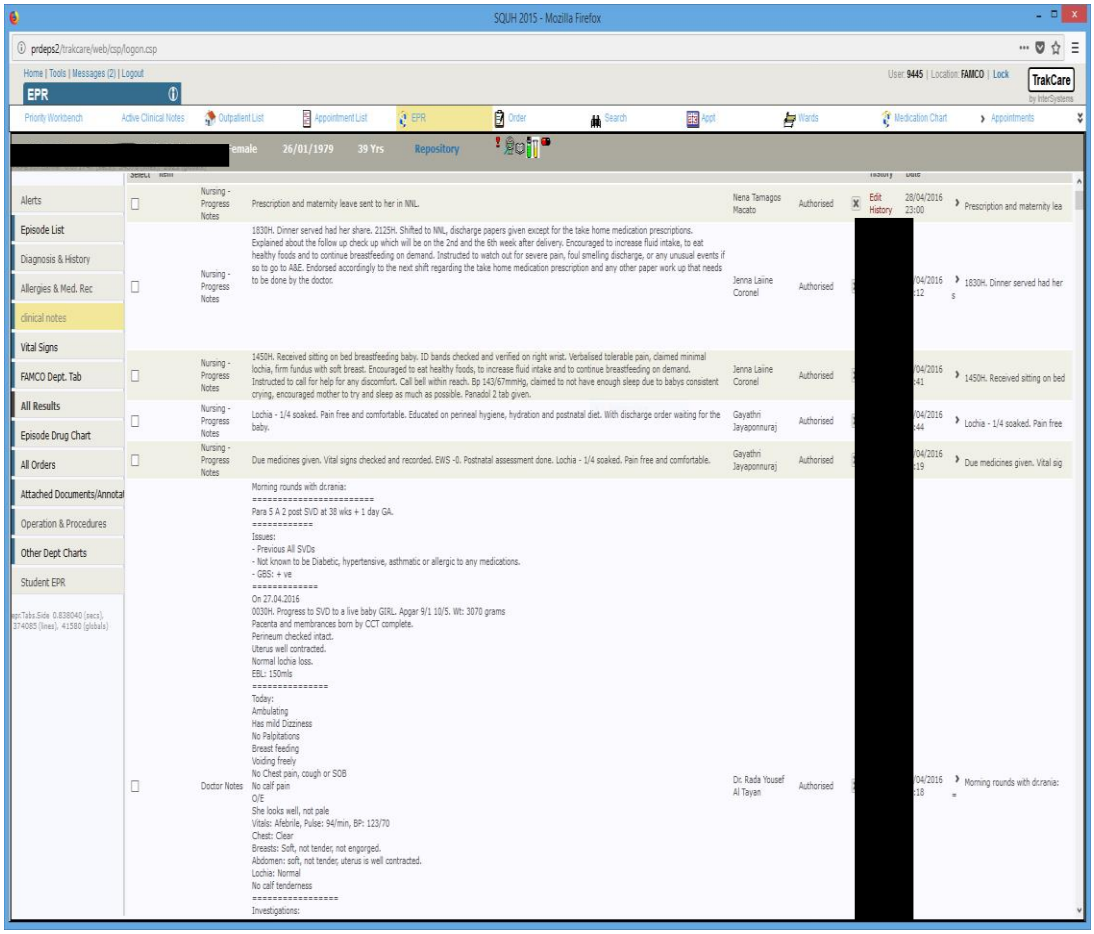
2- Patients' hospital visits page

This displays patient's outpatient clinic visit from ward or emergency room admissions. The researcher followed each patient's clinical notes at each pregnancy to collect the required information



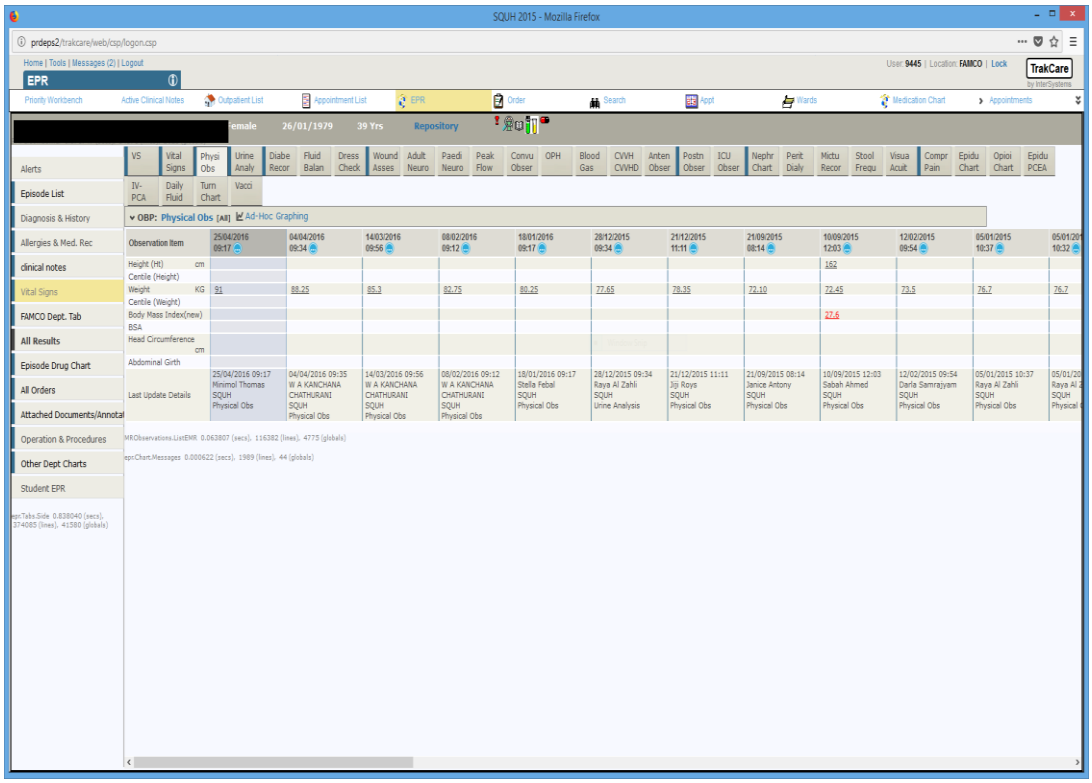
***Patient and healthcare providers are anonymised**

3- Clinical notes by healthcare providers for a selected patient's visit (here was during a ward admission post-delivery)



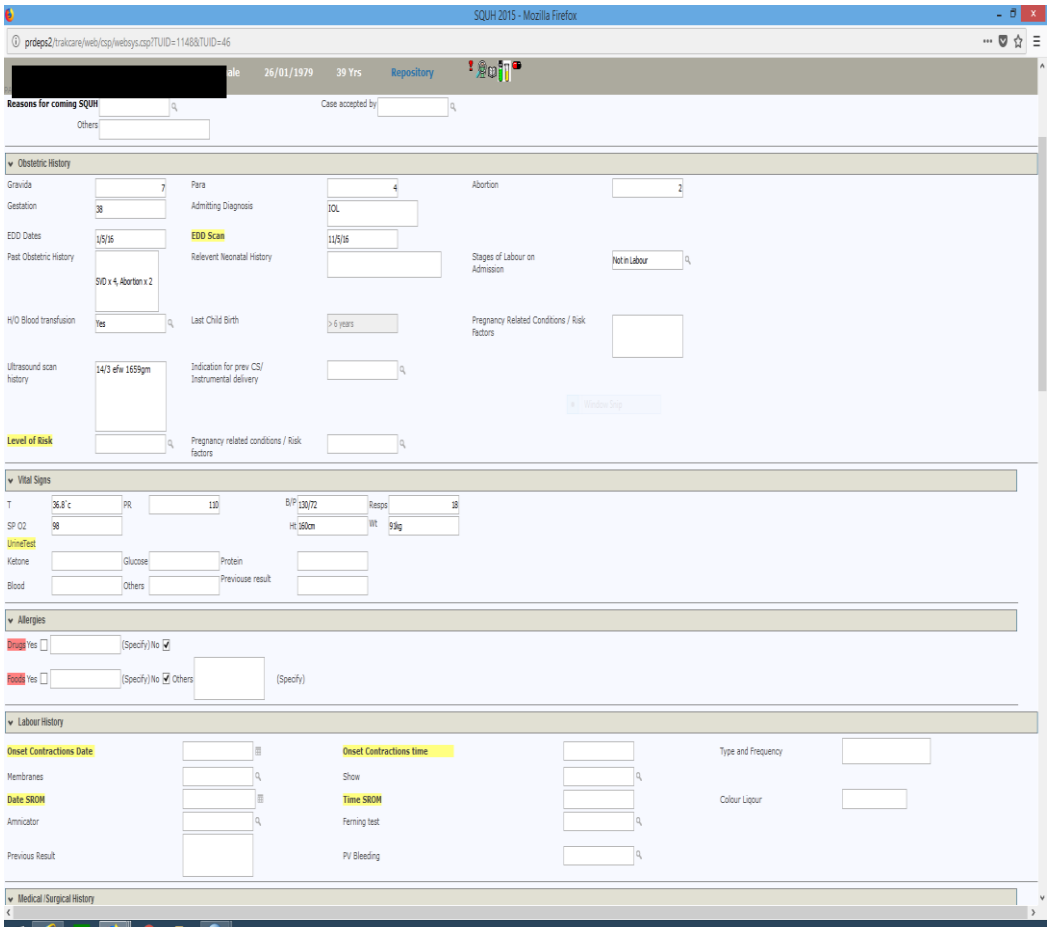
***Patient and healthcare providers are anonymised**

4- Patient's weight recordings at different hospital visits during pregnancy



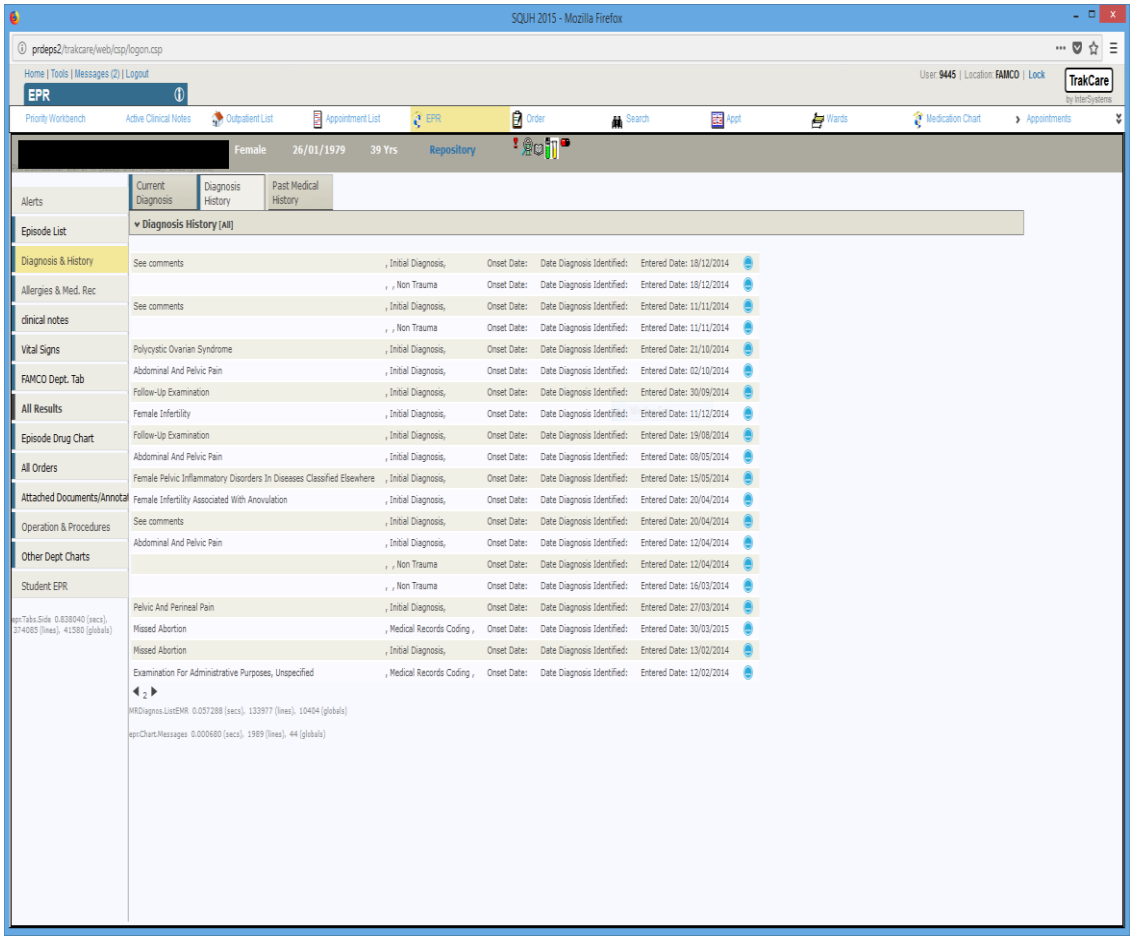
***Patient and healthcare providers are anonymised**

4- Patient's information in a delivery room/theatre



***Patient and healthcare providers are anonymised**

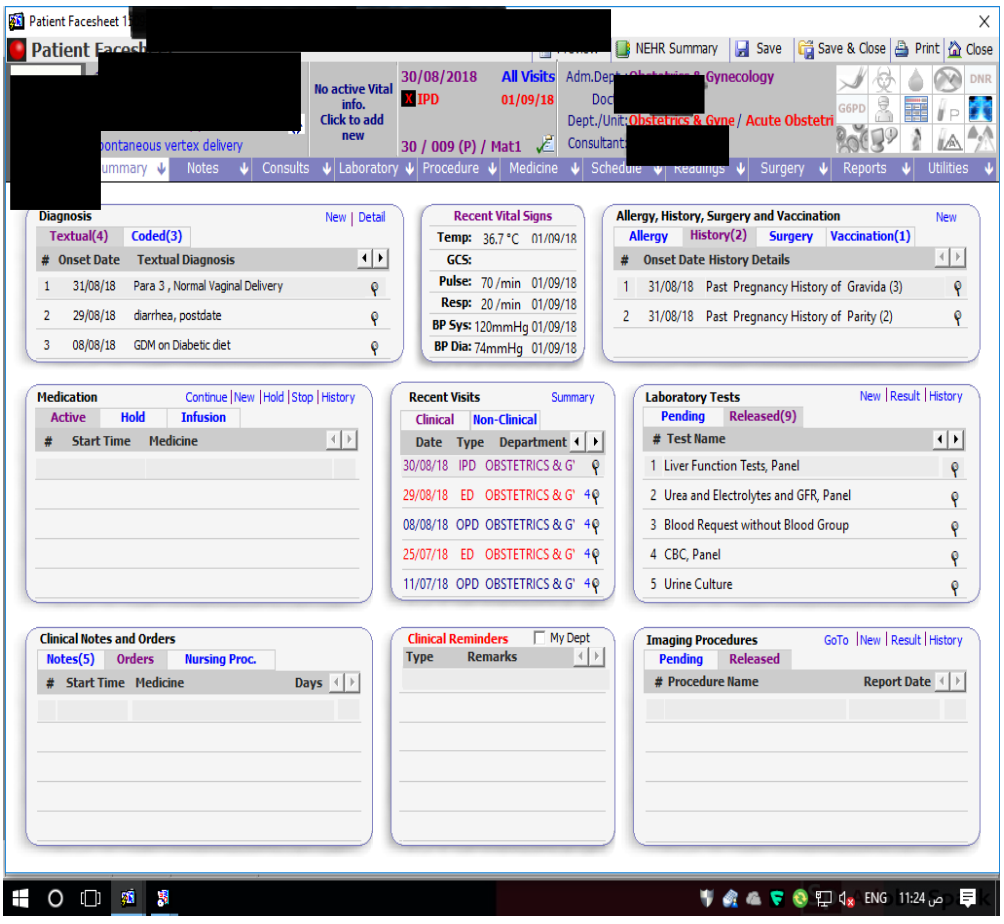
5- All the International codes of disease classification (ICD) assigned for a patient by physicians in different hospital departments during patient's hospital visits



***Patient and healthcare providers are anonymised**

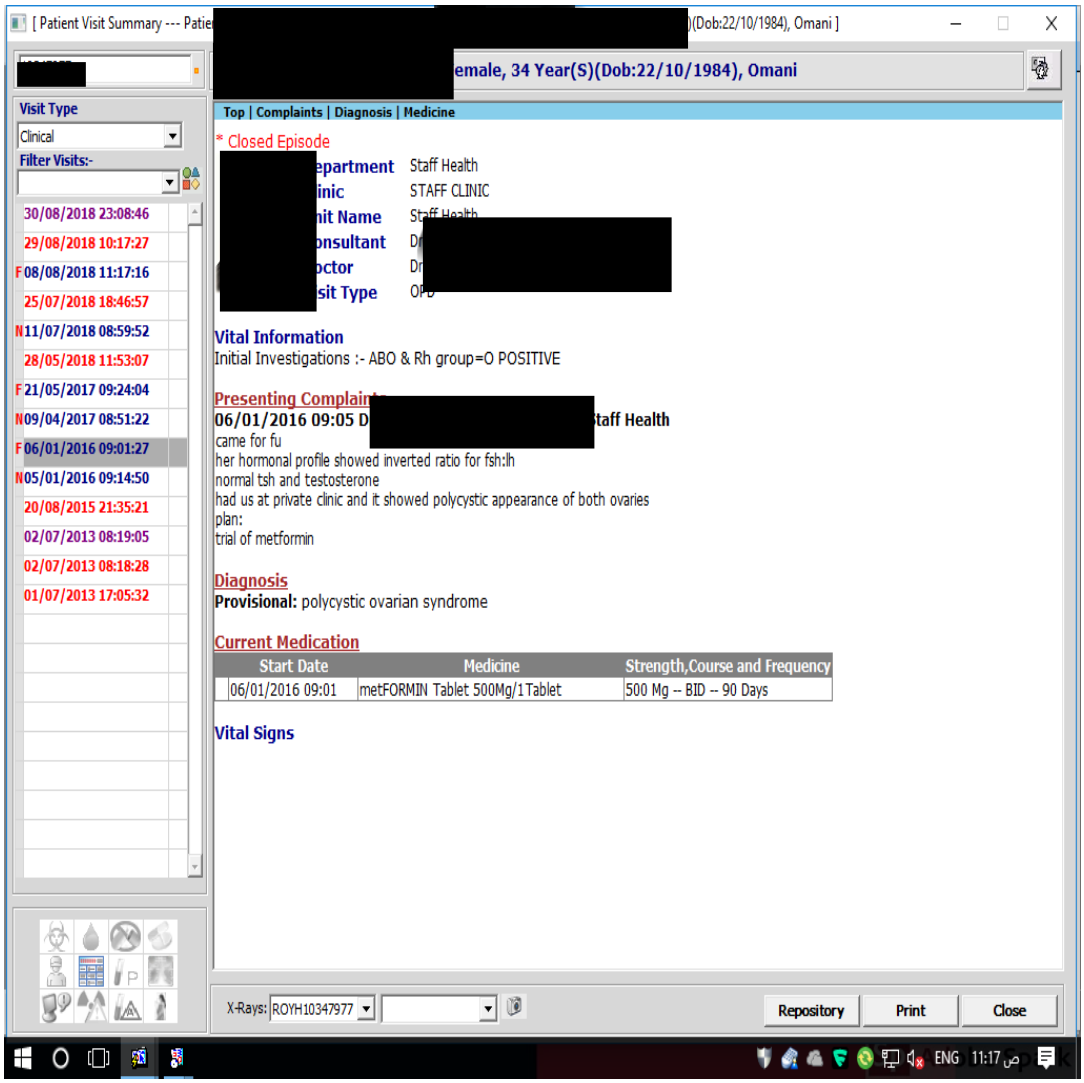
Appendix B2: Royal hospital health information system (ALShifaa)

1- Patient's (face-sheet): A summary of patient's visits, tests, vitals…etc. to navigate through when accessing patient's hospital file



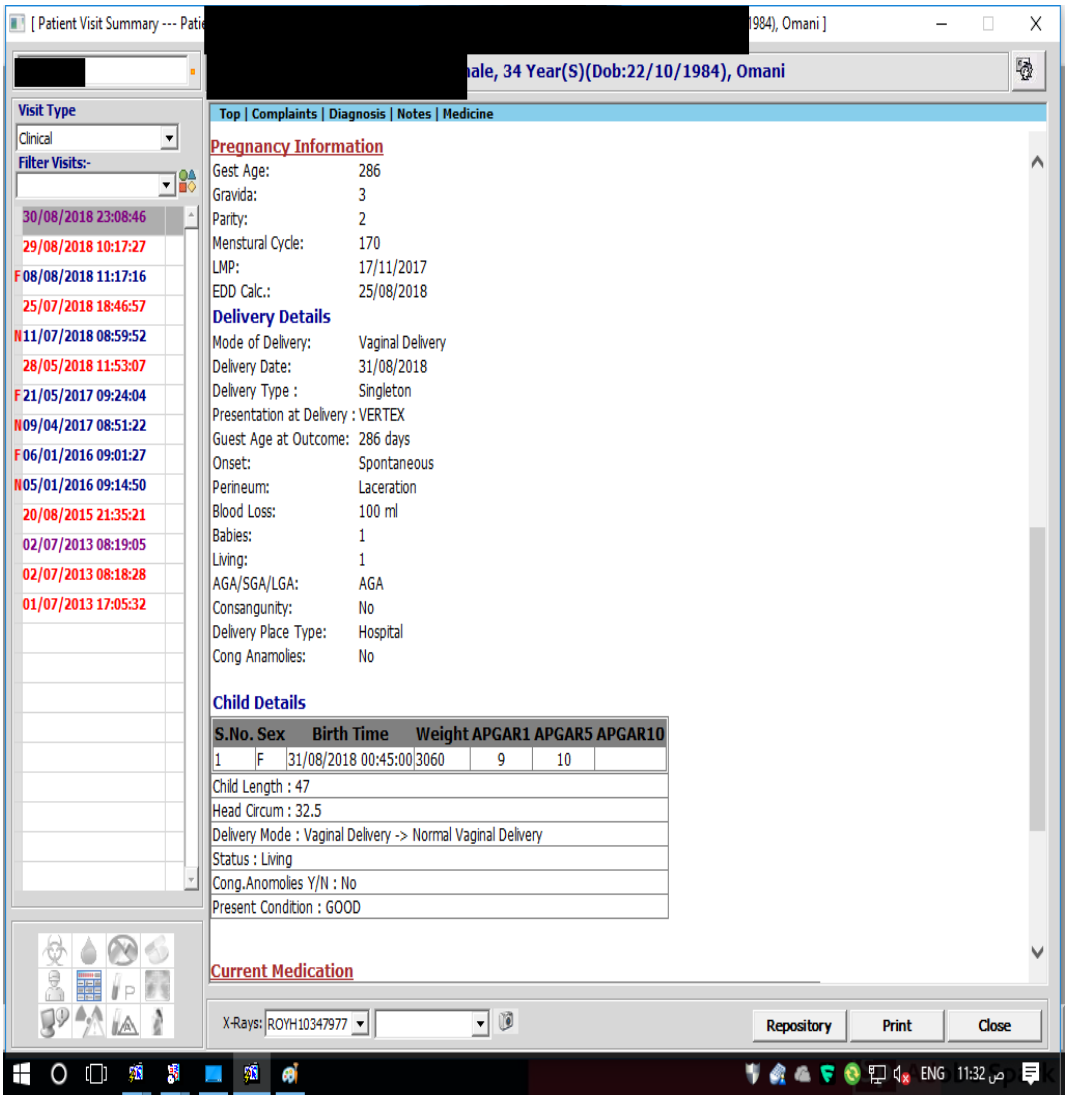
*Patient and healthcare providers are anonymised

2- **Patient's clinical notes at a selected hospital visit (here at an OB/GYN clinic, the assigned ICD code always appears at the bottom under "Diagnosis", here: poly cystic ovarian syndrome)**



***Patient and healthcare providers are anonymised**

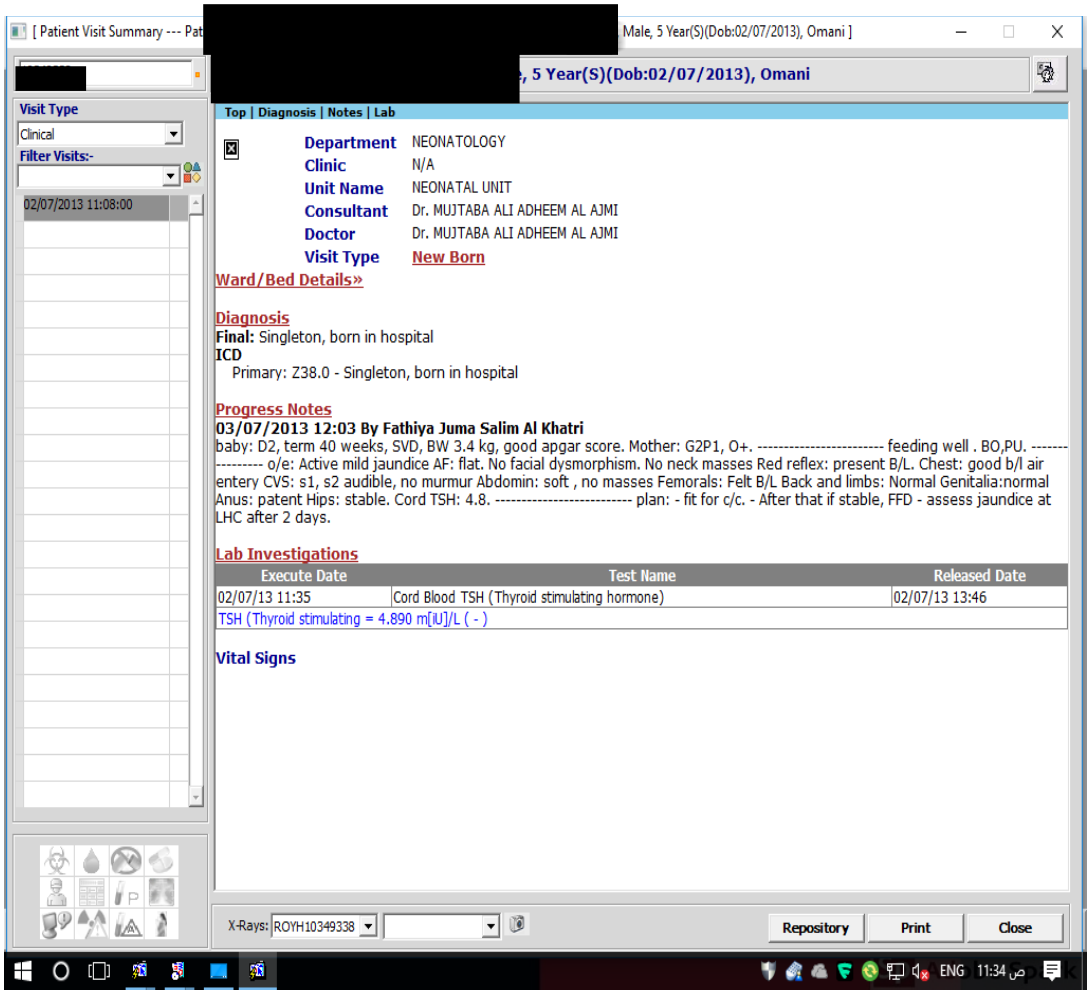
4-Patient's delivery notes and newborns' information



***Patient and healthcare providers are anonymised**

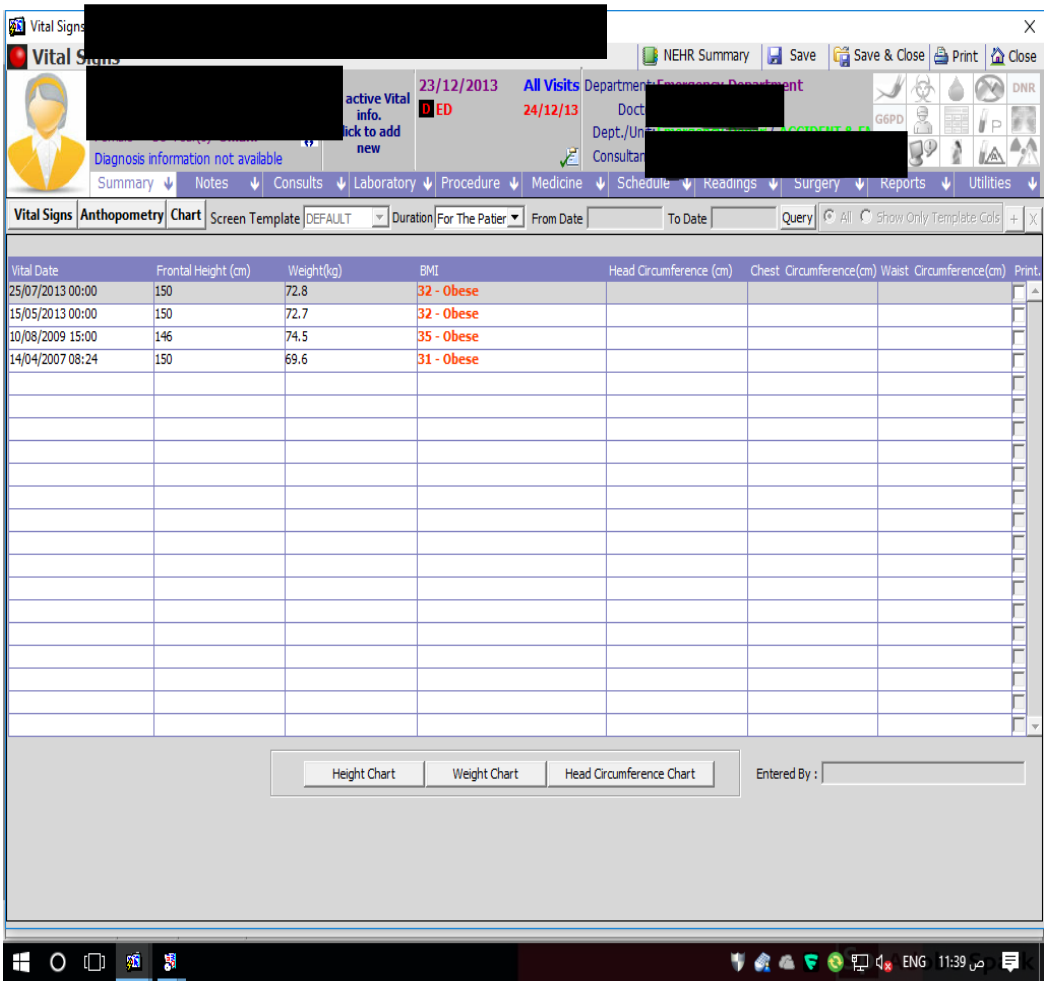
5- Newborn's notes by a neonatologist

Newborn's health profile is connected to mother's health profile and can be easily accessed through it, this was further checked by the researcher to check for any additional information on newborn's status post delivery



***Patient and newborn are anonymised**

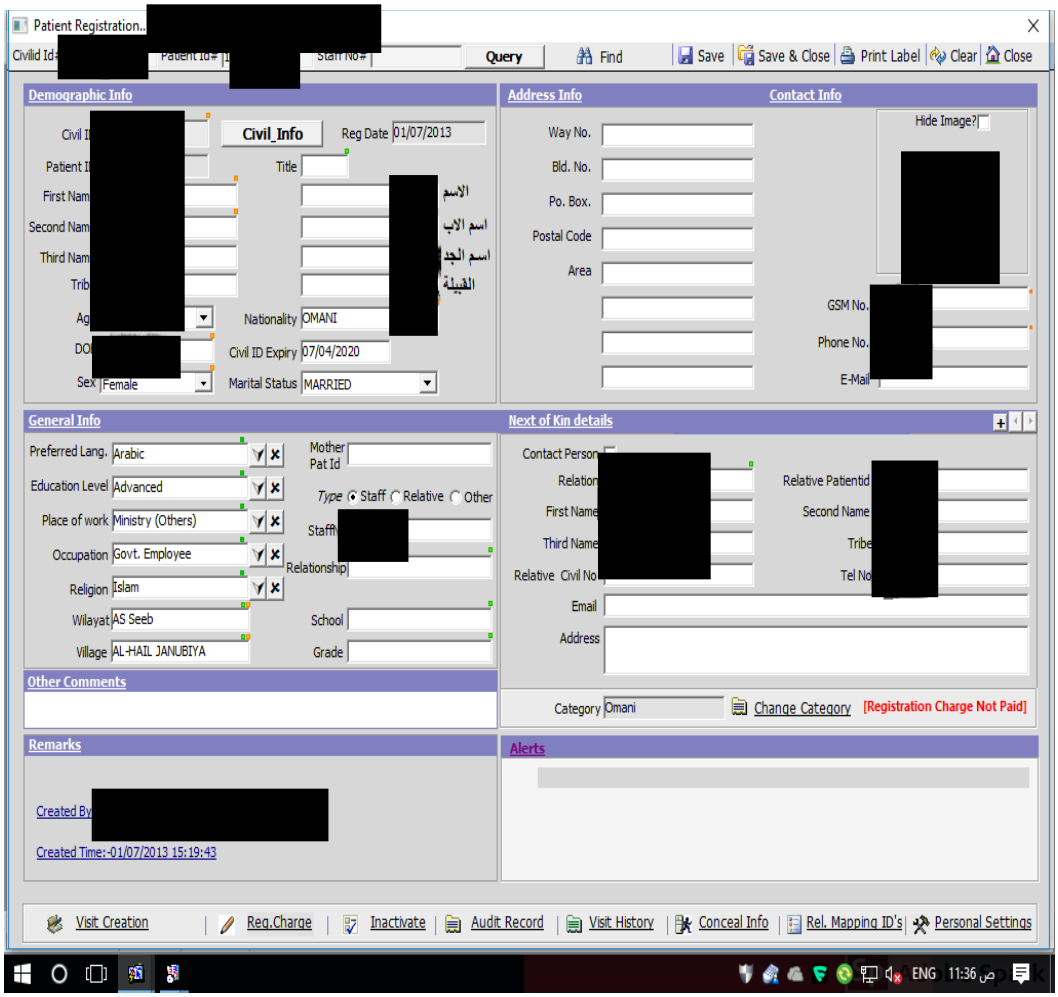
6- Patient's weight measurements at different hospital visits



***Patient and healthcare providers are anonymised**

7- Patient's civil information

Patient's information on residence, educational and employment levels were obtained accessing patient's civil status which is systematically connected to patient's health records



***Patient's personal information is anonymised**

Appendix C : ICD 10 codes for pregnancy and delivery

A)Pregnancy related codes [O00-O08]

O00 ectopic pregnancy

O01 hydatidoform mole

O02 other abnormal products of conception

O03 spontaneous abortion

O04 medical abortion

O05 other abortion

O06 unspecified abortion

O07 failed attempted abortion

O08 complication following abortion and ectopic molar pregnancy

B)Delivery related codes [O80-O84]

O80 single spontaneous delivery

O81 Single delivery by forceps and vacuum extractor

O82 single delivery by caesarean section

O83 other assisted single delivery

O84multiple delivery

Appendix D: Dataset variables dictionary

Variable name	Variable label	Variable description	Variable type	Variable categories	Variable unit
MRN	Medical record number	Unique hospital number given to patients	numerical		
age_yr	Age in year	Participant's age	numerical		year
hospitalname	Hospital name	Name of study hospital	categorical	SQUH RH	
new_dob	Date of birth	Participant's date of birth	date		
agecat	Age category	Participant's age category	categorical	15-20years 20-25years 25-30years 30-35years 35-40years >=40years	year
residence	residence	Name of participant's city of residence	string		
residence_cat	Residence category	Type of participant's residence area	categorical	Rural Urban	
edu_level	Educational level	Participnat;s educational level	categorical	Primary or less Secondary University or college	
employment	Employment status	Participant's employment status	categorical	No Yes	
gravida	gravida status	Participant's gravida status(total number of previous pregnancies and including current pregnancy)	numerical		
gravida_cat	Gravida category	Category of participant's gravidity	categorical	1 2 3 >=4	
preg_ID	Pregnancy ID	A sequence number of participant's pregnancies(regardless of gravidity)in the dataset, same sequence number is given for multiple gestations)	numerical		

baby_ID	Baby ID	A unique sequence number given to each foetus per woman	numerical		
para	parity status	Total number of participant's living kids (p.s in practice multiple kids are counted once in the para status and will be indicated of their presence in the notes)	numerical		
para_cat	Para category	Category of participant's parity	categorical	1 2 3 >=4	
prev_miscarriage	previous miscarriages	Number of participant's previous miscarriages	numerical		
Prev_miscarriagecat	Previous miscarriage category	Category for the number of participants' previous miscarriages	categorical	0 1 2 3 >=4	
prev_stillbirth	previous stillbirths	Number of participant's previous fresh still births(death of foetus at time of delivery or right after delivery, where resuscitation is possible))	numerical		
Prev_stillbirthcat	Previous still birth category	Category for the number of participants' previous still births	categorical	0 1 >=2	
prev_ectopic	Previous ectopic	Number of participant's previous fresh ectopic pregnancy	numerical		
Prev_ectopic_cat	Previous ectopic category	Category for the number of participants' previous ectopic pregnancies	categorical	0 1 >=2	
prev_IUFD	Previous IUFD	Number of participant's previous IUFD((intrauterine death of foetus after 24 weeks of gestation and before time of delivery, where resuscitation is not possible)	numerical		

Prev_IUFD_cat	Previous IUFD category	Category for the number of participants' previous IUFD	categorical	0 1 >=2	
birth_order	Birth order				
PCOS_status	PCOS status	Participant's diagnosis of PCOS	categorical	No Yes	
assisted_pregnancy	Assisted pregnancy	Participant's conceiving method	categorical	Natural Metformin Clomid IUI IVF	
no_of_fetus	Number of foetuses	Number of foetuses in a pregnancy	numerical		
No_of_foetus_cat	Number of pregnancy category	Category for number of foetus in a pregnancy	categorical	1 2 >=3	
Date x	Date of weight x recording	Date of participant's weight x recording	date		
Weight x	Weight x recording	Participant's x weight	numerical		kg
Source x	Source of weight x recording	Source of participant's weight x recording	categorical	OB/GYN clinic A&E Other clinic	
Height	height	Participant's height	numerical		cm
Fx_DM	Family history of diabetes	Participant's family history of DM	categorical	No Yes	
Fx_HTN	Family history of hypertension	Participant's family history of hypertension	categorical	No Yes	
GDM	Gestational diabetes mellitus	Participant's diagnosis of gestational diabetes	categorical	No Yes	
PIH	Pregnancy induced hypertension	Participant's diagnosis of pregnancy induced hypertension	categorical	No Yes	
preeclampsia	preclampsia	Participant's diagnosis of preeclampsia	categorical	No Yes	
term_delivery	Delivery at term	Participant's weeks of gestation at delivery(term >=37<42)	categorical	No Yes	
miscarriage	miscarriage	Participant's pregnancy outcome of miscarriage	categorical	No Yes	
ectopic	ectopic	Participant's pregnancy outcome of ectopic	categorical	No Yes	

stillbirth	Still birth	Participant's pregnancy outcome of stillbirth	categorical	No Yes	
new_dateoo	Date of outcome	Date of participant's pregnancy's outcome	date		
wks_gestation	Weeks of gestation	Pregnancy's weeks of gestation by time of pregnancy outcome	numerical		week
delivery_mode	Delivery mode	Mode of delivery	categorical	Natural Assisted Elective C-section Emergency c - section	
preterm_wks	Weeks of preterm delivery	Pregnancy's weeks of gestation if delivery was preterm(<37weeks>24)	numerical		week
birth_wt	Birth weight	Baby's weight at birth	numerical		kg
macrosomia	macrosomia	Diagnosis of macrosomia in a new-born(birth weight>4.0kg)	categorical	No Yes	
LWGA	Low weight for gestational age	Diagnosis of low weight for gestation in a newborn(birth weight <10th percentile for gestational age)	categorical	No Yes	
NICU_ad	NICU admission	New-born's admission to neonatal intensive care unit	categorical	No Yes	
Low_APGAR	Low APGAR score	Diagnosis of low APGAR score in a new-born(a score of <7 out of 10 at five minutes after birth in assessing new-born's Appearance, Pulse, Grimace, Activity, Respiration.A a scale is given from 0 to 2 on each measure at 1 and 5 minutes after birth)	categorical	No Yes	
clinical_bio	Clinical or biological evidence	Presence of clinical or biological features of PCOS in a participant's(i.e features of acne, scalp hair loss, excess hair growth on face	categorical	No Yes	

		and body and obesity)			
radiological	Radiological evidence	presence of radiological features of PCOS in a participant's(i.e presence of cysts on ovaries)	categorical	No Yes	
oligo_anovulation	Oligo or anovulation evidence	Presence of oligo or anovulation in a participant as part of PCOS features(i.e irregular or absence pf menstrual period)	categorical	No Yes	

Appendix E1: Ethical approval forms

1- Ethical approval from Sultan Qaboos University Ethical Committee



Sultan Qaboos University
COLLEGE OF MEDICINE & HEALTH SCIENCES

جامعة السلطان قابوس
كلية الطب والعلوم الصحية

REF. NO. SQU-EC/193/16
MREC #1377

To: Dr. Hana Al Sumri
Department of Family Medicine and Public Health
Sultan Qaboos University

Subject: *Approval of the Research Project*
"The Effects of Poly Cystic Ovarian Syndrome (PCOs) on Pregnant Women in Oman and the Associated Psychosocial Aspects of Infertility among Affected Women"

Date: 08th November 2016

Thank you for your response to the comments raised by the Ethics Committee (EC), COM&HS, SQU regarding the abovementioned research project which was reviewed and discussed during the EC meeting of 29th September 2016.

The modifications and clarifications submitted in response to the comments were discussed for reconsideration during the EC meeting of 27th October 2016 and were found to be satisfactory. Therefore, the research project submitted is now **approved.**

I wish you a productive study with your research work.

With kind regards,

Prof. Mansour Al Moundhri
Chairman, Ethics Committee
COM&HS, SQU

cc: Dr. Khalid Al Balushi, Asst. Dean, Postgraduate Studies & Research, Sultan Qaboos University

Appendix E2: Ethical approval from Royal hospital- Research and Ethical Review and Approve Committee



Sultanate of Oman
Ministry of Health
Directorate General of Planning & Studies

سلطنة عمان
وزارة الصحة
المديرية العامة للتخطيط والدراسات

Ref. MoH/DGPS/CSR/PROPOSAL_ APPROVED /45/2016

Date : 13.12.2016

الرقم :
التاريخ :
المرفق :

Hana AL-Sumri
Principal Investigator

Study Title : **"Poly cystic ovarian syndrome in Oman: Effects in pregnancy, psychosocial aspects of infertility and quality of infertility care from patients' and professionals' perspective"**

After compliments

We are pleased to inform you that your research proposal **"Poly cystic ovarian syndrome in Oman: Effects in pregnancy, psychosocial aspects of infertility and quality of infertility care from patients' and professionals' perspective"** has been approved by Research and Ethical Review & Approve Committee, Ministry of Health.

Regards,

Dr. Ahmed Mohamed Al Qasmi
Director General of Planning and Studies
Chairman, Research and Ethical Review and Approve Committee
Ministry of Health, Sultanate of Oman.

Cc
Day file

P.O. Box: 393, Postal code 100, Muscat, Tel:24601161, Fax:24696533

ص . ب : ٣٩٣ ، الرمز البريدي : ١٠٠ ، مسقط ، هاتف : ٢٤٦٠١١٦١ ، فاكس : ٢٤٦٩٦٥٣٣

Appendix E3: Ethical Approval from University of Nottingham-Research Ethics committee-School of Medicine

The University of Nottingham

Direct line/e-mail
+44 (0) 115 8232561
FMHS-ReschEthics@nottingham.ac.uk

Faculty of Medicine and Health Sciences

Research Ethics Committee
C/o Faculty PVC Office
School of Medicine Education Centre
B Floor, Medical School
Queen's Medical Centre Campus
Nottingham University Hospitals
Nottingham
NG7 2UH

30th November 2016

Dr Hana ALSumri
Medical Doctor, PhD Student
c/o Dr Manpreet Bains
Research Fellow, Division of Epidemiology & Public Health
School of Medicine, Clinical Sciences Building
Nottingham City Hospital Campus
Nottingham University Hospitals
Hucknall Road, Nottingham
NG5 1PB

Dear Dr ALSumri

Ethics Reference No: OVS14112016 – please always quote	
Study Title: Poly cystic ovarian syndrome (PCOS) in Oman: Effects in pregnancy, psychosocial aspects of infertility care from patient's and professional's perspective. **Short Title:** Poly cystic Ovarian syndrome in Oman: from effects in pregnancy to the experience of infertility and infertility care.	
Chief Investigator/Supervisors:, Dr Lisa Szatkowski, Lecturer in Medical Statistics, Dr Jack Gibson, Assistant Professor Epidemiology & Public Health	
Lead Investigators/student: Dr Hana ALSumri, Medical Doctor/PhD Student	
Other Key Investigators: Dr Manpreet Bains, Research Fellow, Dr Linda Flaschi, Research Fellow/Data Analyst, Division of Epidemiology & Public Health	
Type of Study: Overseas study, PhD project, mixed methodology qualitative/quantitative	
Proposed Start Date: 12/2016	**Proposed End Date:** 31/12/2018 24mths
No of Subjects: 1,100+	**Age:** 18+years
School: Medicine	

Thank you for submitting the above application which was considered by the Committee at its meeting on 14th November 2016 and the following documents were received:

- FMHS Research Ethics Committee Application form dated 26/10/2016
- Sultan Qaboos University Hospital Ethics Outcome comments dated 11th October 2016
- Proposal Summary dated 25/10/2016
- Participant Information sheet – Patients v2 16/10/2016
- Participant Information Sheet Health Care Professionals 12/10/2016
- Consent form - English v2 16/10/2016
- Interview guide - Health Care Professionals 12/10/2016
- Interview guide – Patients 12/10/2016

These have been reviewed and are satisfactory and the study has been given a favourable opinion.

A Favourable opinion is given on the understanding that all appropriate ethical and regulatory permissions are respected and followed in accordance with all local laws of the country in which the study is being conducted and those required by the host organisation/s involved.

A favourable opinion is given on the understanding that the conditions set out below are followed:

The University of Nottingham

1. Please submit copies of letters of permission/approval from the Sultan Qaboos University Hospital (SQUH) and The Royal Hospital (RH) Health Research Ethics Board when these are available for our records.

2. If any changes are required to the project you should follow the procedures required by the SQUH and RH Health Research Ethics Boards for notification and submission. Please inform this committee by sending copies of the changes and approvals for information and the records. Additional review will not be required and these can be noted.

3. You must notify the Chair of any serious or unexpected event.

4. An End of Project Progress Report is completed and returned when the study has finished (Please request a form).

Yours sincerely

pp

Professor Ravi Mahajan
Chair, Faculty of Medicine & Health Sciences Research Ethics Committee

Appendix F: The psychosocial effects of infertility among affected Omani women with PCOS and their satisfaction with healthcare services in fertility clinics

Appendix F1: Study information sheet

Title of Study: The Psychosocial Effects of Infertility among affected Omani Women with PCOS and their satisfaction with healthcare services in fertility clinics

Name of Researcher(s): Hana ALSumri, Dr.Manpreet Bains, Dr.Lisa Szatkowski

We would like to invite you to take part in our research study. Before you decide we would like you to understand why the research is being done and what it would involve for you. The principal researcher will go through the information sheet with you and answer any questions you have. Talk to others about the study if you wish. Ask us if there is anything that is not clear.

What is the purpose of the study?

This study aims to explore the psychosocial aspects of infertility among Omani women with PCOS. It also aims to gain a better understanding of patients' experiences and views on the health services received in infertility clinics, including the extent to which emotional and physical needs of women are discussed. This will help us to make recommendations for interventions to better support this group of women.

Why have I been invited?

You are being invited to take part because you are receiving care from the infertility clinic and diagnosed with poly cystic ovarian syndrome (PCOS). We are inviting around 20 individuals with PCOS and who are receiving care in the infertility clinic to take part.

Do I have to take part?

It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and 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. This would not affect your legal rights or your health care.

What will happen to me if I take part?

If you are interested in taking part a researcher will arrange a time to carry out an informal interview when convenient for you. Interviews can be carried out in a private room during your next clinic appointment, at your home or somewhere of your choice; you can choose which suits you best. Before the interview starts, the researcher will explain what will happen and if you are still happy to take part you will need to sign a consent form. The interview will begin by understanding how you were first diagnosed with PCOS and subsequent infertility and then explore your experience living with it. Later the interviewer will try to understand how you have been managing and the sources of support available to you. Finally the researcher will explore your experience with the health care received in fertility clinics and how this could be improved. The interview should not take longer than 45 minutes. A voice recorder will be used to record the interview so that the researcher does not have to take notes.

What are the possible disadvantages /advantages of taking part?

Whilst there are no foreseeable disadvantages of taking part, we cannot promise that the project will help you personally, but your views and experiences with the services in fertility clinic may help us to understand and identify ways in which consultations could be improved in the future.

What if there is a problem?

If you have a concern about any aspect of this study, you should ask to speak to the researcher who will do her best to answer your questions. The researcher contact details are given at the end of this information sheet. If you remain unhappy and wish to complain formally, you should then contact the Research Ethics Committee Administrator, Sultan Qaboos University, College of Medicine and Health Sciences. E-mail:mrec@squ.edu.om.Telephone Number:24143427 or Ministry of Health ethical committee ,E-mail dr.h.a.alharthi@gmail.com,Telephone Number:24599688

Will my taking part in the study be kept confidential?

We will follow ethical practice and all information about you will be handled in confidence.

If you join the study, some parts of the data collected for the study will be looked at by authorised persons from the University of Nottingham who are supervising the research. They may also be looked at by authorised persons from the University of Nottingham for translation purposes. All will have a duty of confidentiality to you as a research participant and we will do our best to meet this duty.

All information collected is strictly confidential and any personal information will be deleted from interview transcripts. You will be assigned a unique code that will not identify you in any way. Quotes used in any reports or publications will not

identify you in any way. The voice recordings will be kept securely by the researcher conducting this study, on a password-protected computer.

Your personal data (e-mail/address, telephone number) will be kept for one year after the end of the study so that we are able to contact you about the findings of the study *and possible follow-up studies* (unless you advise us that you do not wish to be contacted). All other data (research data) will be kept securely for 7 years at the University of Nottingham (UK) backup servers. After this time your data will be disposed of securely. During this time all precautions will be taken by all those involved to maintain your confidentiality, only members of the research team will have access to your personal data.

What will happen if I don't want to carry on with the study?

Your participation is voluntary and you are free to withdraw at any time, without giving any reason. However, any interview data collected prior to withdrawal may still be used in our analysis.

What will happen to the results of the research study?

The voice recordings from the interviews will be analysed by the research team to see what opinions the group had about the topics discussed. The results may be presented in scientific journals and at conferences. If you would like to receive a summary of the results please let us know, however please bear in mind that this may be some time after your participation as the results have to be analysed.

Who is organising and funding the research?

This research is being conducted as part of a PhD degree of the principal researcher from the University of Nottingham (UK) and is funded by Sultan Qaboos University.

Who has reviewed the study?

The Research Ethics Committee at Sultan Qaboos University and Ministry of Health has reviewed this study and approved it.

Further information and contact details

Hana ALSumri

Department of Family medicine and Public Health
College of Medicine
Sultan Qaboos University
ALKhoud/AL-Seeb

Tel: +968-99623773 **Email:** alsumry@squ.edu.om

Thank you for reading this information sheet and considering taking part in this project.

Please keep a copy of the information sheet.

Appendix F2: Consent form

CONSENT FORM

Title of Study: <u>The Psychosocial Effects of Infertility among affected Omani Women with PCOS and Their Satisfaction with the healthcare services in fertility clinics</u>

REC ref: MREC 1377 (SQUH)/14122016(RH)

Name of Researcher: Dr Hana AlSumri

Name of Participant: **Please initial**

1. I confirm that I have read and understand the information sheet for the above study and have had the opportunity to ask questions. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason. I understand that should I withdraw then the information collected so far cannot be erased and that this information may still be used in the project analysis. ☐
3. I understand that relevant sections of my data collected in the study may be looked at by the research group and by other responsible individuals for monitoring and audit purposes. I give permission for these individuals to have access to these records and to collect, store, analyse and publish information obtained from my participation in this study. I understand that my personal details will be kept confidential. ☐
4. I understand that the interview will be audio recorded using a digital recorder and that anonymous direct quotes from the interview may be used in the study reports. ☐
5. I understand that information about me recorded during the study will be kept in a secure database. If the data is transferred it will be made anonymous. Data will be kept for 7 years after the study has ended and then securely destroyed. ☐
6. I agree to take part in the above study. ☐

Name of Participant Date Signature

Name of Person taking consent Date Signature

Appendix F3: Interview guide

Study Title: The Psychosocial Effects of Infertility among affected Omani Women with PCOS and Their Satisfaction of The Healthcare Services in Fertility Clinic

Name of interviewee: Hana AL Sumri

Interview Guide

Aim

To understand the psychosocial experience of infertility among women diagnosed with PCOS in Oman and to explore their views on the health care received in infertility clinics.

Objectives

1. To explore the psychosocial effects of infertility among Omani women with PCOS.

2. To explore women's views on the health care services received in infertility clinic in Oman.

Introduction

- Thank them for their time and acknowledge that it is not an easy topic to talk about and we are grateful for their participation. Then explain the purpose of the interview in general.
- We would like to hear about your experience of infertility and your views on the healthcare services you have been in contact with.
- Statement on confidentiality, right to withdraw consent, recording of the interview.

We would like to reassure you that all data you provide will be kept strictly confidential by the research team. The voice recording of this interview and any quotes used in study reports will not identify you in any way. Your participation is

- Check they have read the information sheet.
- Read information sheet and gain verbal consent
- Ask if the participant has any questions before starting the interview.
- Check still happy to take part and that consent form has been signed

A) Psychosocial aspects of infertility

1. Can you tell me when you were first started to try for a baby?

- Probe around feelings at that time

- How did this impact on husband and their relationship?
- Probe around role of others

2. Can you tell me where things are at the moment (medically)?

3. Have you found anything particularly difficult during this time? (Being unable to conceive and trying for a baby)?

- What are your biggest concerns?
- Are you worried about anything in particular?

4. Do you know other people who are close to you and trying for a baby as well?

- a soft introduction for the following question

5. How do you think infertility is perceived in our society?

- How do you feel about this?
- Probe around any social pressures? From whom?

6. Can you relate to any incidents/stories you have faced or heard about, related to infertility and society's reaction?

- to better understand society's perception

7. How do you think our society perceives adoption?

8. Can you see it as an option for you?

- Why? Based on answer

9. How do you think you have been coping with infertility till now?

- Has anything in particular helped you to cope?
- From where do you get support?
- Have you made any changes in your life to help you cope? Probe around health/lifestyle changes? Psychosocial changes?

10. Tell me how do you think your husband is coping?

- Have you talked to anyone other than your husband about it? Who? What were their responses?

B) Experience with health system

1. What made you seek medical help?

- Who did you go to initially?
- What happened?

2. Can you talk me through what happened when you first attended the infertility clinic?

- How did you feel about attending this appointment for the first time?

3. What were your expectations?

4. What happened – what was discussed?

- Need to continually check how they felt about things being discussed and essentially whether they felt comfortable enough to ask questions. If they did experience any distress, did they feel this was managed/acknowledged by the healthcare professional? Have you been told about the cause of your infertility

5. Was there a plan? What was this?

- How comfortable were you with the treatment plan?
- How much you were involved in it? Were you allowed to ask questions?
- Were you given alternatives? Have your feelings been checked?

6. Were you given follow up appointments? Tell me about them

- Find whether they have been seeing the same provider (and how important is this), and whether they dealt with any other HCPs.

7-Tell me more about the nature of the tests, procedures done?

- Check how comfortable they were with them, how prepared were they beforehand?
- What worries they have, how they perceived them, how clear information was? Did it meet expectations?

C) Experience with health care providers

1. Can you tell me a little bit about the healthcare providers that you have seen in the infertility clinic?

-the gynaecologists, nurses, social worker, radiologists…etc. check who have they been seeing regularly

2. What is your general feel of the environment in fertility care?

- How comfortable you felt to speak up to HCPs? Were they supportive
- Any language barriers? Gender differences? Adequacy of consultation time? Privacy?
- How easy was it to open up or ask questions?

3. To what extent have you received emotional support during consultations?

- Probe based on answer what factors helped or did not help that?
- If yes, whom of the team offered more support? Why you think so?
- How did they think the healthcare provider responded to any emotional distress?

D) Trust in current health system

1. How much do you trust the medical system in treating your condition?

- Why? (Whether YES or NO to previous question)

2. Have you ever tried to seek help from anywhere else (outside the medical domain)? If yes, where and why?

3. In your opinion, is there any way your-follow ups can be improved?

E) Closing remarks

- Is there anything else you want to add?
- Re-assure about confidentiality
- Thank participants for their time

F) Patients' characteristics (check list if not mentioned at any point)

Age:

Residential region:

Educational level:

Employment status: Yes NO

Years of marriage:

Years of trying to conceive:

Years of starting infertility treatment:

Succeeded to carry a pregnancy before Yes NO

If yes how many times:

Appendix G: Framework of the themes of the qualitative study: The psychosocial effects of infertility among affected Omani women with PCOS and their satisfaction with healthcare services in fertility clinics

Appendix G1: Theme 1: Self-perception of infertility

Sub-theme1: Religious and spiritual beliefs

Theme 1: Self-perception of infertility **Sub-theme1: The role of hopefulness, religion and spirituality**		
Participants	**Hopes in conceiving**	**Faith in God's will**
SQUH1	Motivation and excitement at each appointment as it carries the hope to get pregnant and her believe in god's will to cure her and grant her children	
SQUH2	The couple's hope is still present despite going through failed conceiving attempts and they believe in seeking treatment with hope	A person should be satisfied with what God has decided for him/her and seek solutions and one cannot run away from destiny She prays to God to have strength and be blessed with kids, she also attends a sheikh(religious man) who recites verses of the holy Quran on her to help her get pregnant
SQUH3		"If God is willing we will be given a child at any moment and very soon." "He is so generous" She makes sure to read specific verses of the holy Quran on a daily basis and prays to God, her family encourages her to always attend to a Quran reciter
SQUH4	Husband's words of hope to his wife" Allah(God) will send you the child at the right time"	
SQUH5	She believes of herself being still young and have got the chance to have kids and she is not afraid yet about the delay, she also makes sure not to miss any appointment and reminds herself of them continuously	She is satisfied for what God decided for her and will be happy with whatever the result would be because it will be what she deserves
SQUH6	She has the hope to experience motherhood and she is not afraid of that not happening, she	She has no issues in accepting the situation as it is her destiny and this delay might be for a good reason

	also believes there must be a solution for each problem and that God will satisfy her in a way or another	
SQUH7	She is not concerned about the two years of pregnancy delay as she is still young and was busy with her studies but she has the hope that she will get pregnant soon	
SQUH8	"But Inshaa Allah(with God's will) there is a way and hope to be treated and have children later"	She reminds herself each time she gets emotionally affected that its God's decision and if he decided not to bless her with children it will not happen and she should be satisfied with that She asks God to have children during at each prayer
SQUH9	Very optimistic about what God decided for her and believes if he decides to bless her it will happen un-doughtily	She has a faith that children are gifts from god and they should be optimistic to receive it from him She adheres to religious activities to get strength and hope
SQUH10	After the experience of miscarriage she holds on hope to conceive again and a way to forget her last experience this hope is related to the advances in treatment options nowadays	She has faith of what God has chosen for them if that is to be childless
RH1		
RH2	God is generous and she is willing to keep trying till the last day of her life and she has strong hope to find the treatment and willing to travel to wherever its available at any cost	Believe of it being their destiny and what God has chosen for them her husband said once comforting her "if you know where I can buy children, please tell me where and I will go and buy them...it is our destiny after all" When she gets negative thoughts she comforts herself with prayers and by reciting the Quran
RH3		
RH4		"I always said that the pregnancy delay is Allah's (God's) decision" She finds emotional support by getting close to God and getting connected to religious friends, as one has to be a good believer
RH5	She is convinced that she has to have hope otherwise her life would be miserable and she prays to God to continue having hope and not to give up	Sometimes she gives up on everything including praying and thinks it's of no use but then she repels and pray again to God to give her strength
RH6	She has a hope to get pregnant as she does not suffer from anything	

	serious and treatment is advanced nowadays	
RH7		Although she is afraid of treatment failure she is still has faith in God's will
RH8	She always believed she can get pregnant and that god will give them a child soon	She finds support by joining a group of women with the same issue who rely on reading specific verses of holy Quran to help them get pregnant as some got healed and carried a pregnancy after joining this group and she tries to be close to god and prays to him in the middle of the night to find emotional comfort
RH9	She tries to have hope in God's will and live her life normally and not be miserable because of this	
RH10	She is happy to suffer from fertility treatment just for the hope to conceive	Accepting her destiny and believes if God has not decided for her to have a child nothing is going to work even if she tried the best treatment

Sub-theme2: The impact of infertility on participants' emotions

Theme 1: Self-perception of infertility **Sub-theme2 The impact of infertility on participants' emotions**					
Participants	**Loneliness**	**Jealousy**	**Sorrow and sadness**	**Inferiority**	**Guilt as they cannot fulfil Husband's needs**
SQUH1	Feeling of loneliness especially when her husband is at work and she stays all by herself and she thinks loneliness is a killer				
SQUH2	Loneliness is a disturbing issue and she gets rid of it by getting occupied with other things				

SQUH3	She used to baby- sit her niece and she enjoys the time with her and her laughter fills the house with happiness				"when he sees children you feel that he wish if he has children like anyone"
SQUH4	Feeling lonely sitting in the house doing nothing but on her phone for long hours				
SQUH5			"Honestly, sometimes I burst into tears or go up into my room and keep crying."	The way people comment about her pregnancy delay affects her and decreases her self-efficacy and personality significantly in a negative way	"Because he loves children very much and he likes to see children around him"
SQUH6		Watches her husband's attention to his nieces and nephews and feels jealous as she wishes to get him a child of his own instead	The discussions about children in her workplace affects her emotionally and she gets an emotional break down when she gets back home She got pregnant before and everything was fine with the baby then she miscarried suddenly and it was a very difficult experience to		"All I want is to have a child to satisfy my husband more than satisfying myself, it is all because of me he is childless"

			her psychologically to the extent she didn't want to visit any hospital after that		
SQUH7			She used to cry whenever she discovers a new issue with her medically		She watches her husband experiencing fatherhood with his nephew as his parents are divorced as this is the only way where he can practise fatherhood
SQUH8	The house feels so empty and depressive and how her husband tries to get occupied not to spend time in it	She gets annoyed knowing about relatives' pregnancy news and tries to avoid going to places where children are with her husband as she cannot withstand his attention to them	She did not expect that she will face troubles with pregnancy and it has affected her emotionally and each time she sees the doctor she becomes miserable and so upset	She explains how people make her feel in an inferior position and she feels that she doesn't get appreciated by her friends as she do not have children	She knows how much her husband loves children and is desperate to have his own so she avoids telling him about her negative pregnancy test results and avoids going to public places where there are kids because she feels guilty of not being able to fulfil this wish for him and it hurts her when he mentions that he does not have a child to spend time with
SQUH9		She envies the women who get pregnant right after marriage	She allows herself to grief and get angry from any situation that frustrates her about pregnancy delay and she thinks at one stage she might need to get a	She gets this feeling of being different than others when she visits relatives and carry their kids and the look she gets from them makes her feel uncomfortable	Her husband tells her "I do not want to use my compassion with other kids I want it to be for my own child"

			psychological support		
SQUH10	It is difficult to be alone and feeling life is empty especially if not employed so she occupies herself to run away from the negative thoughts she get when alone		"I cannot say that we are ok and we do not get affected by what people say, it makes us sad" She has miscarried twice ,the second time the baby was big and she went into an emotional break down but learning from the experience she promised herself to grief for few days only and then move forward and be optimistic		"As a man I know it is impossible that he does not want children, but I'm not able to give him that"
RH1	She loves to spend afternoons walking outside the house not to feel the loneliness and boredom			People look at a woman with pregnancy delay as a woman with a disability	
RH2	Because her husband has to leave every two weeks for work away from home she spends time in her family house not to feel lonely at home alone	She feels jealous to see other women with kids but then she prays to God to be blessed as well	"Dreams...I always dream to have a child but I then realize that it is a dream and not a fact and I feel sad and it hurts me" "yes it was on my first day after the miscarriage...I stayed for two days without talking to	People look at women with infertility differently as if they have a defect	

			anyone and was in a mental breakdown"		
RH3		She feels upset to see her friends with their kids in gatherings and being the only one childless		In our community if you have a pregnancy delay you will be bullied being labelled "Infertile"	She blames herself for being the reason of not fulfilling her husband's need to have children
RH4	Tries hard to distract her husband and change the daily routine for him so he does not feel bored from being alone at home by themselves	She felt jalousie from her father in law's attention to her pregnant sister in law		Initially she did not notice that people look differently at her but then she realized that they hide news of pregnant women in the family and avoid having their kids around her worrying of her envy	Her husband still has hope for her to get pregnant but she feels he is missing something when he sees children, lately he got very attached to his niece which makes her feel so guilty
RH5	She makes sure to leave the house every day to exercise to avoid sitting alone by herself	She admitted about feeling jealous seeing her husband's attention to other kids			Her husband is fathering his nephews as his sister is a widowed and they live with them and it hurts her to see his love to them and that she cannot get him children of his own
RH6	Intentionally she spends long hours at work place to avoid being all by herself at home		She struggles emotionally in her work place when colleagues discuss children issues	People hide their pregnancy from her and try to avoid her ,once a friend told her about her pregnancy and asked her not to be upset about it	She got hurt when her husband told her how he sees his friend playing with his son and that he had a dream about having a son of his own but then cried when he found it was just

					a dream and she felt so bad as it is the first time he shares his feeling with her
RH7		She does not like to know about pregnancy news among women in the family	No one will know what she feels until they experience it themselves and it irritates her whenever someone talks about pregnancy where she tries hard to hide her feelings		She knows how important it is for her husband to have children but he does not show her that but she notices his constant struggle to look for different treatment options for her
RH8	Tries to occupy herself especially during day time when her husband is at work to avoid loneliness	She is envying her sister in law who got married later and got children already as they live together with their in laws	She got affected emotionally from pregnancy delay mainly due to society's constant pressure and questioning	People look at her with no mercy and she started avoiding women gatherings especially if pregnant women are around as they look at her inferiorly ,especially that she got married before them	
RH9	After work she spends time out the house in the evenings so she does stay alone at home		"At the beginning I used to be upset about it and ask why this is happening to me "	Her husband's family look at her as if she is less than them because of her pregnancy delay	
RH10	Living alone and being unemployed drives her crazy	She feels pain to see pregnant women around and feels jealous to see her father's attention	"So my parents are old and happy now with my younger sisters' children...it is true that sometimes it hurts my feelings but	She narrated her experience once in a health centre where a survey on mothers was being carried out and the researcher	She knows how her husband loves children and people used to call him Abdullah's father, so he calls any child he sees "Abdullah" and she wishes to

		to her pregnant sister	what can I do, I cannot do anything."	approached her and when she knew she has no children she told her "you are not of any use to me" this made her feel being different to other women	make this true for him

Sub-theme 3: Fears and concerns about infertility and its consequences

Theme 1: Self-perception of infertility **Sub-theme 3: Fears and concerns about infertility and its consequences**		
Participants	**Not to experience motherhood**	**Concerns around chance of conceiving reducing with increasing age**
SQUH1	Participant expressed her fear of the possibility of treatment failures and not carrying a pregnancy ever	She gets the thoughts of having less chances to get pregnant as people age that is why she is in hurry to conceive, although she is still in her twenties
SQUH2	She was comparing herself with her husband as her desire to have a child is much stronger as motherhood is a nature among women	Discussed her husband's refusal to do tests earlier during their marriage but after they have completed 4 years he started to realize that they are aging and they should start seeking treatment
SQUH3	She keeps asking God to bless her with at least one child and all what she wants is to get pregnant and be a mother	
SQUH4	She is concerned of not succeeding in getting pregnant as she wants a child so bad	
SQUH5		
SQUH6	Expressed her desire to carry a pregnancy to be a mother for herself and not just to satisfy the people around her	
SQUH7		
SQUH8	Participant expressed her concern of being told by the doctor one day that she is sterile and will never have children, as she cannot imagine not to experience motherhood	She looks at old people who do not have children to look after them in that age and how do they suffer and she is worried to end up being like them in the future

SQUH9		She have always wished to have a child early to grow up with, now she is concerned that she is approaching her 30s and chances to conceive will start to be less	
SQUH10			
RH1	"As a woman I need to be a mother and I need a child"		
RH2		"My concern mainly is that I'm getting older and I need to have a child as soon as possible"	
RH3			
RH4			
RH5		"I am getting old without any children yet" One of the reasons of wanting a child for her is to look after her in older age, she tells about her old widowed aunt who does not have children and how she is abounded now and no one takes care of her	
RH6			
RH7	Expressed that having a child is all what she needs to be able to experience motherhood and live a happy life		
RH8		Growing old and not having children around is a source of constant worry as chances to conceive get less	

RH9			
RH10	The desire of wanting to be a mother occupies her thoughts and she wishes to have a child and hear him call her “Mama” before she dies and she is worried that she might never get to experience this	She thought of the option of adoption fearing to be left alone at an old age	

Appendix G2: Theme 2: Cultural aspects around infertility

Sub-theme 1: Beliefs around child bearing

Theme 2: Cultural aspects around infertility **Sub-theme1 : Beliefs around child bearing**		
Participants	**Infertility is always attributed to the woman**	**Infertility is caused by envy and an evil eye**
SQUH1	People in the society attack anyone who has a delay in pregnancy and will label them to "infertile" as pregnancy is expected right after marriage Her in laws keep on fetching in her family's history to confirm that the delay is hereditary	People try to convince her it is evil eyes that causes the delay and she should be treated for it Relatives keep telling her about success stories of women who went for traditional medicine but she is not convinced
SQUH2	The community will expect pregnancy few months after marriage and will keep asking about it	People around try to send hints talking in front of her about people who had the same problem got treated with Quran as they were envied
SQUH3	The people wait to hear about pregnancy quickly after marriage She feels threatened as people do not stop pushing her husband to marry another woman	After starting medical treatment with no success people started to say it might not be a medical cause behind this
SQUH4	Women will be labelled to be "infertile" and blamed for it by people before knowing the results of the investigations Elderly relatives will start suggesting to husband to marry another woman once there is a delay ,as they do not accept any delay in pregnancy after marriage She is annoyed by the elderly women of the family who keep talking about the need for her husband to start looking for another wife	

SQUH5	The in laws immediately concluded that she is the one causing the problem Her in laws started to think she is infertile only after one year of pregnancy delay The in laws refer to pregnancy delay in her sister and brother and are convinced that she will be like them She hears hints so often from her husband's family giving suggestions for her husband to remarry	Her mother in law is not convinced with medical treatment so she wanted to take her to be treated by Quran as she might be envied
SQUH6	Her husband's family blame her that she does not care and do not want to be treated	She was complaining of other things along with pregnancy delay like fatigue and insomnia and many people advised her to get treated from evil eye
SQUH7	The pressure starts from the in laws right after marriage on the couple to have kids as soon as possible Her sisters in law keep telling her they will make their brother marry another woman as he should have children	Relatives kept telling them you must have been envied by others and that is why you cannot conceive She is convinced about traditional treatment and feels it is safer and more effective than medical treatment
SQUH8	She looked back in her family's history for similar cases ,she found few but they got blessed later with children after the delay so she tries to convince herself it cannot be hereditary as people say She knows that the society will not accept a man to stay without children and will keep pushing till her husband marries again	she got affected by people's pressure and attended the healer but figured out that he was not a religious man but a witch instead
SQUH9	They keep pushing her assuming she is the one causing the problem without knowing it for sure.	Even that she is not convinced about evil eye to be the cause of the delay ,people's continuous talk

	She once told her mother in law to give them a break and stop mentally pressurizing them as her son needs rest, so she took it personally and kept saying back to her son your wife is saying it's your fault in the delay and she will make fun of you in front of people Her husband is the eldest among his brothers and his family expected a child from him right after marriage, she narrates a story of a couple who had a delay for one year where the husband was forced to remarry again and both his wives got pregnant later at the same time People were looking at her family's history of pregnancy delay to confirm her inherited infertility Her father in law's personality is very influential and she is afraid that her husband will listen to his father's advice and marries another woma	about it made her believe in it
SQUH10	She found it funny when people started to ask her to look for treatment after they have completed one year of marriage without even checking whether they are having a problem in conception or intentionally delaying it	
RH1	People in the society blame women in general for pregnancy delay and blame her for not making effort in seeking treatment	A colleague advised her to go to someone who reads Quran to free her from any envy or evil
RH2	Her in laws want children for they son as soon as possible and do not want to wait	People told her it is envy that sometimes makes the uterus get displaced so they advised her to go for

	Her brothers in law push her husband to marry another woman and they tell him they will choose a bride for him	"rubbing" (a traditional treatment)
RH3	People expect pregnancy right after marriage Her sister had a pregnancy delay for 7 years but her husband was causing the problem so now people started to ask after her family more to confirm its hereditary Her husband's family will recommend their son to marry again even if the pregnancy delay is for a short time	Many people told her about "rubbing" technique and traditional treatment but she refused to try it
RH4	The test of her husband's semen sample showed that it is infected but the husband refused to accept the result	
RH5	Elderly women in the community do not accept a delay in pregnancy and will always say it is a woman's fault "My sister had the same problem and one day they said that I will be like my sister…I can't forget this word until now"	
RH6	She was waiting for the pregnancy right after marriage as it's the norm in the society but then realized there is a problem when it did not happen	She was convinced by her friend who suffered from the same problem to visit a traditional healer but she did not benefit from it
RH7	She is frequently being questioned about the delay comparing her with all the ones who got married after her and got pregnant "instantly " Her mother in law told her once "If my son decided to remarry I will find him the right girl	Her sister in law had a positive experience with "rubbing" so she tried it as she might be lucky like her but she was not

RH8	She knows how people automatically put the blame on her for the delay even if they do not say it to her directly She expected the pressure from the people around as she knows they would expect pregnancy by the end of first year of marriage	
RH9	She is burdened by questions from elderlies about the delay and the constant blame on her There is a similar cases of pregnancy delay in her mother's side but she believes it is not an inherited issue as her in laws hint towards	"Others have lots of children by now?!" you might have been envied by someone" and have been advised to go get treated by Quran as a family member got pregnant using this method but she still does not believe in it
RH10	Her mother in law does not know about their investigations or who is causing the problem but she assumed that it is from her and keeps annoying her, the man is always fine and cannot have any defect	She is not convinced by people's recommendation to go to traditional healers as she is afraid to be affected negatively

Appendix G3: Theme 3: Living with infertility

Sub-theme 1: Social pressure and expectations

Theme 3: Living with infertility **Sub-theme 1: Social pressure and expectations**			
Participants	**Constant comparisons**	**Frequent questioning**	**Judgmental comments**
SQUH1		Women keep asking about how many kids she have got and since when she has got married	She gets embarrassed by her in laws' comments during women gatherings saying that she is infertile and should get treated
SQUH2	She hears hints from people who talk in front of her about	People are being so nosy and ask about personal issues related to her pregnancy delay	

	other couples who got married recently and are already expecting a child		
SQUH3	She gets questioned directly about her pregnancy delay and was told X got married after you and she is pregnant now	They will keep asking why I am not pregnant until now?! What is going on?! Is there anything wrong?!	People talk in front of her so she gets to listen about infertile women and how their husbands got married again to have children
SQUH4		Everybody was asking her "Aren't you pregnant yet?!" "When you are going to be pregnant? After two years of marriage?!"	Once she was in a funeral when a lady from her husband's family saw her husband and told him in a loud voice so that she could hear "I wish this was your second wedding and not a funeral"
SQUH5	She hears a lot of things like "All women who married after you have children now and you are not yet", women would also tell her you are behind of everyone and those who got married after you are expecting now	"Why are you having a pregnancy delay? and why you are not pregnant until now?!"	
SQUH6		Husband's family insists to be obtrusive and want to know about all the investigations and treatments and cannot understand this is supposed to be confidential between the couple	Sometimes she travels with her husband for leisure and people will comment and say "You should have travelled for treatment first"

SQUH7	She continuously get questioned about the delay and gets compared to her sisters in law who got married around the same period and all are with children	The pressure is from husband's family and they keep asking and telling her that they need to see their son's child	
SQUH8		She get questioned about pregnancy each time she visits her in laws	She gets a lot negative comments whenever she spends time with relatives' kids as she is does not have the experience to deal with them
SQUH9	She gets compared immediately to anyone who gets pregnant in the family	Her in laws keep asking and tracing her menstrual period each month to be able to tell if she is pregnant or not	She hears from people that a husband shouldn't pamper his wife or love her if she cannot get him children and during her friend's conversation about children's care they point out to her that she does not understand their suffering with children and their care as she has no children unlike them
SQUH10		People keep asking "why are you not pregnant yet?!", "Why don't you seek treatment?!" they always ask, "Is there anything coming soon?" an expression used culturally to ask about pregnancy among newly weds	
RH1	People say X delivered a baby already what are you waiting for?	She gets annoyed from frequent questioning about her medical treatment of infertility and she feels these are personal issues	Once she was leaving her neighbour house when she was asked "Why are you not pregnant yet? Do you think you are still young?!"
RH2		People do not stop talking about pregnancy delay and	People tell her "Why you do not let your husband marry another woman?!" and it

		they question ”Why you don’t have children yet?!” ”Did you find a treatment for your condition?”	irritates her husband to the extent he would say let me know where they sell children so I can go and buy them one, for that her sister in law in each time she sees her she will ask “Have you bought children yet?”
RH3	She gets compared to her sister in law who got married after her and she has a child, “Everyone got married after you have children now and you don't yet"	“I was very annoyed every time I have been asked about it "why?!" and it’s the frequent questioning that annoys her the most	
RH4		Questioning about the delay from her in laws started after their second year of marriage and it is putting a lot of pressure on her	
RH5		She gets frequent questions about the delay from the elderly of the family especially during weddings and gatherings and they want to know who causes the delay whether it is her or her husband	She was bullied by one of the aunts who miscarried few times and ended up with no children but she says at least she had carried babies in her womb before unlike her who have never
RH6		Her husband’s family used to ask a lot about it but now they have been told how much does it annoy her and they have stopped	A woman once approached her in a gathering and placed her hands over her tummy and asked her “Are you pregnant but hiding it?!”and she was so embarrassed as other people were around
RH7	The pressure from society is escalating given all whom they know got	Other people were negative all the time and mention this issue a lot especially her in laws who keep on	She was once bullied by one of her husband’s relatives when she went to visit her sister in law who has just delivered, a lady said about

	children especially her husband's younger brother who got married after him and has a child and his family is waiting for his baby as he is the eldest	asking "when?!" ”when?” ”when?”	her that she stops her husband from practising sexual intercourse with her that is why she does not get pregnant. In addition they will stop her whenever she participates in women talks about delivery and children's care as she has not been through it and thus got no experience
RH8	“I am living with my parents-in-law and his brother married after us and got children and I was thinking too much and they are comparing us with them, one day it was Eid and we were sitting in a big hall, full of women and girls and a lady told me "How long you will be waiting for to have children?! and all those who got married before and after you got children now"	People ask "Why are you not pregnant yet?!" and "Why didn't you go for that woman who treats people with herbs?!" or "Why didn't you do this or that?!",to an extent a relative said I will keep asking you each month until you get pregnant	She is annoyed by this one women from her husband's family who keeps asking her each time about pregnancy delay and tells her “if you don't wish to have children our son do” and once she looked at her tummy and told her “Are you pregnant but lying to us that you are not?!”
RH9	“Others have done it already?!" or "Others have lots of children now?!"	"Why are you not pregnant yet?!" or "Why is taking you so long?” ,the pressure is so much mainly from the elderlies in the family	
RH10		Her mother in law keeps on asking her about the pregnancy delay and warns her about her chances getting less by aging	

Sub-theme 2: Coping mechanisms

Theme 3: Living with infertility **Sub-theme 2: Coping mechanisms**					
Participants	**Husband's support**	**Self-distraction**	**Adopting a healthy lifestyle**	**Social adjustment**	**Coping gets easier the longer infertility persisted**
SQUH1	"He is always standing next to me and he still till now is doing so"	She used to think a lot about pregnancy delay but decided to continue her studies and she got employed as well to keep herself occupied	Despite being busy with work she makes sure to walk for at least 30 minutes every day to keep fit		She was feeling very different at the beginning going through this experience but now she is feeling much easier to live with it
SQUH2	Her husband calms her down and reminds her that it is their destiny and they should be satisfied	She feels lucky to be living next to her family's house to hang out with them and not feel lonely, she also looks up for different life coaching lectures and attends them		Her husband and her moved out of their in laws to their own house and she tries to avoid negative people and not respond to their comments	"All I can say is Alhamdullilah (Thank God) I got used to it and I get less affected now by people words"
SQUH3	Her husband is always optimistic and keeps on telling her that	She occupies her time by sewing traditional Omani clothes			

	one day God will bless them with children	using different materials and sell them			
SQUH4	Her husband asks her to be optimistic and tells her it might not be the right time for them		She started to eat healthier and avoids all junk and thought it might be her weight that delays pregnancy so decided to start losing weight through exercise		
SQUH5	Her husband stands against his family's comments to his wife about the delay and he lifts her spirit and tries all means to strengthen their relation	She occupies herself by doing household work but also she has a hobby for putting (henna) to brides as a home based business	She practises physical activity by walking daily for 20-30 minutes	Whenever her husband is away for work she sleeps over in her family's house to have a break from her in laws and their constant questioning	
SQUH6	Her husband is her first supporter and he helps her to get through society's pressure	She decided to start an educational degree to keep herself occupied	She follows her physician advice in subscribing to a gym to lose weight to help her get pregnant, she also thinks it is beneficial for her	Recently she started to isolate herself socially to avoid peoples' questions	

			regardless of its effect on pregnancy's success		
SQUH7	Her husband is always by her side and would support her treatment and do whatever it takes to help	She decided to study another degree since she has not been employed and have no kids and her husband has his own business to occupy him	She reduced fatty food and meat intake and started to take more of fruits and vegetables as it might help her condition		
SQUH8		Her husband occupies his time after work hours outside the house and for her she will try to keep busy by household work, reading and watching TV, she used to give so much attention to her husband details but it used to annoy him		She used to be social but now she avoids social gatherings including avoiding to hang out with her friends as they continuously speak about their children which makes her feel odd among them	She got used to treatment now unlike before and she understands her condition better as she got used to it
SQUH9	Her husband tries to be optimistic for her and asks her to be optimistic for him as well	She distract herself trying to stay so she decided to read one positive statement each day and started to engage in		Her husband decided to move out of his parent's house due to their controlling nature on their life	

		different social activities			
SQUH10	Her husband always stands by her side and feels her suffering with fertility medications and asked her to take a break from treatment	She makes sure to keep herself busy all the time whether babysitting family children or get involved in various social activities, she also looks up for different workshops to attend and lean new things. she has started a small home business of selling perfumes. Her husband also spends after work hours in theatre activity as a hobby that keeps him busy too	She enjoys having a good and healthy body and she exercises and eats healthier diet		
RH1		She spends time in doing some had crafts at home and visiting relatives to occupy her time and her husband has got a business to keep him busy as well	She decided to be more fit and exercise with her friends		

RH2		She keeps herself occupied by doing household work and doing some hand crafts	She started to attend a special program for diet and physical activity for at least 1-2 hours a day	She hides her hospital follow ups and her investigations from her in laws to avoid them asking questions and interfering with their life	
RH3	Her husband is her supporter and he supports her to continue treatment when she gets frustrated and thinks to quit	Her husband and her try to occupy their time by travelling to break the daily routine		She lives in her own house and she is more satisfied because it helps her avoid her in laws' annoying comments	
RH4		She likes to do new activities to break the routine and she introduces new ways of doing the daily activities		She believed that living in a flat located in the third floor might have contributed to her pregnancy delay so she moved to another flat on the ground floor	
RH5	Her husband gives her hope if treatment failed and supports her in her treatment journeys	She spends her time mostly doing household work and looking after her sheep	She makes sure to be physically active and walk every day as it helps her feel good and comfortable	She avoids socializing and attending gatherings to avoid peoples' comments	Her husband's attention to his nephews used to make her jealous but now it is easier for her to cope

RH6	Her husband is always by her side and the one who strengthens their relation when she thinks they should separate because of her being the reason behind infertility	She likes to practise her hobby as a makeup artist, it keeps her busy and she enjoys it, her husband also practise photograph y and they both get occupied with these activities after work hours			Now she is used to peoples' negative comments as she is stronger than before emotionally
RH7		Her husband started a new business after work hours and it keeps him busy		She started to isolate herself from people despite being very social in nature and she admitted that she came up with acceptable excuses just to move out from her in law's house to avoid them annoying her about this issue	
RH8	Her husband is more patient than her and always supports her and promises not to leave her because of this	Her husband spends long hours in his work and she occupies her time doing house work, recently she decided to look for a job		She gets emotionally affected by attending women's social gatherings ,she tries to avoid their look and their comments,	She got used to the whole situation by now

	infertility issue			her husband had to go to another mosque as men started also to annoy him about being childless	
RH9	He keeps encouragin g her and stopping her from having negative thoughts	After work she will make sure to have something to do whether it is house work or spend the evening with her husband outside the house	She decided to adopt a healthy lifestyle with her husband so they started to eat healthy diet at home and both subscribed to a gym, she feels much better emotionally and enjoys being healthier		She used to be more fragile going through the whole experience but with her husband's support she is stronger now
RH10		She used to live in a room in her in law's house and used to spend her time cleaning and decorating it but after so many years passed she got bored and asked her husband to move out of in laws to their own house			She used to get upset whenever she gets asked about her delay but now after 10 years she is much stronger "I'm over it by now"

Appendix G4: Theme 4: Adoption in the Omani community

Sub-theme1: Society's views on adoption

Theme 4: Adoption in the Omani community **Sub-theme1: Society's views on adoption**				
Participants	**Forbidden in Islam**	**Rejection for whom these children are**	**Confirmation of a couple's sterility**	**Not the norm**
SQUH1		It's very hard to accept such a thing unless this child is a family member with known parents such as an orphan niece or nephew		It's very rare to hear about adoption in our society ,no one is doing it
SQUH2				This is the first time to think about it and the idea never crossed her mind
SQUH3		The community is very		She just came to know that it is possible to

		judgmental and she cannot see how they might accept such a thing as she was blamed for baby-sitting her niece when her sister was busy at work and people rejected the idea, so how about if the raised child is a stranger		adopt a child by taking them home ,all what she used to hear is to sponsor orphans financially through sending money to specific organizations
SQUH4		The community rejects these children as they believe they are foundling children	This step is considered as an indication of couple's sterility or they that do not want to try to get treated from infertility	
SQUH5	She is convinced that adoption is forbidden in our religion unlike in the Western countries	She has a neighbour who adopted a boy and the society is still rejecting it no matter how good as a person this child might be, people always refer back to these children's origin and believe they are of unknown parents and was born from a sinful relation		It is considered as a shameful act in our community
SQUH6				
SQUH7				

SQUH8	All what she knows about adoption is that it is prohibited in Islam			This is her first time to discuss this topic ever
SQUH9	A teacher at school used to tell them that adoption is forbidden in the Islamic religion	It is rejected in our society as they are of unknown origin ,a distant family member has adopted a girl and people still cannot accept her in the family		She remembers one of her school teacher who she admired a lot was once talking negatively about adoption and not encouraging it and since then she could not admire her anymore as she agrees with adoption
SQUH10				
RH1				
RH2				
RH3				
RH4			She might accept adoption only if the couple tried for a very long time and could not conceive but if the delay is only for few years then it is not accepted as people will say they must have been told to be sterile to go for this option	The concept of adoption is new to her and she never thought about it before
RH5	Many people believe it is forbidden in Islam because an adopted boy will be considered a stranger to the adoptive mother when		People will always reject it even if they show you that they do accept it in front of you but behind your back the do not and will say you are "sterile"	

	he matures and an adopted girl will be a stranger to her adoptive father			
RH6				
RH7				
RH8	The community accepts children to be adopted if they are orphans of family members as they feel responsible to raise them but not a child of unknown origin	Her in laws will not accept it and the solution is for their son to remarry to have children than to adopt, the community accepts children to be adopted if they are orphans of family members as they feel responsible to raise them but not a child of unknown origin	"I can feel that if I do it they will think that I'm sterile and can never be pregnant"	She does not know anyone who has adopted and she has never thought about it
RH9		The community will reject as they are affecting the family's lineage and no one would want to marry these children in the future		No one has the courage to do it as no one that she knows did it before, there is no awareness about it, if there is then people will start accepting it
RH10		Her husband responded to her adoption's suggestion that his family will not accept not knowing this child's original		

		parents. Then she narrated a story of a relative who has adopted and people still do not accept her among the family although she got married already		

Sub-theme 2: women's views on adoption

Theme 4: Adoption in the Omani community **Sub-theme 2: women's views on adoption**			
Participants	**Limitations in raising adopted children**	**Lack of real compassion towards adopted children**	**Exposing adopted children to unfavourable social situations**
SQUH1			
SQUH2			
SQUH3			
SQUH4		The attachment will not be real as if he was her own child	
SQUH5			When the adopted child grows up and finds out about his adoption he will think that his parents just sympathized with him and that was the reason of adopting him
SQUH6			

SQUH7	Because these children are not their biological children they might not give them the full attention and care needed while raising them		"It might be that the same child himself will experience and hear some inappropriate words because he is not with his real family...so I am refusing this and don not want it to happen"
SQUH8		"the idea of having a child who originally comes from other woman and raises him is very difficult and I will not be compassionate with him"	She does not want to expose the child to community's negative comments
SQUH9		She believes that she will not be able to continue giving them love when they grow up especially towards boys as they will be considered strangers to her and similarly with her husband towards adopted girls	"Why should I bring a child and let people treat him inferiorly and make him feel that he is adopted as he is not living with his parents, I will be the one responsible for this feeling." "It will be difficult for any family to accept him or her for marriage and it will be my fault to put them in such misery"
SQUH10			
RH1	Will not be able to raise these children well as they are not her genuine children, i.e. she cannot scold them or punish them if they make mistakes and would feel guilty if she does		
RH2	It will be sinful to get angry at them if they have done something wrong, so it will be difficult to raise them	She feels she will not be able to love them genuinely as they are not her real children	She does not want the child to be bullied by the community and be being responsible for it
RH3			

RH4		She has the fear not to have a feelings towards them and to deal with them with no love or compassion after adoption	She does not want to put the child in a situation to be rejected by the family and the community
RH5	Raising adopted children will be more of a burden and a responsibility unlike when they are your own children	Raising an adopted child is not a real relationship and the child might have negative feelings towards parent when they grow up and know about their adoption	
RH6			
RH7	She thinks she will not be able to love him/her as if they are her own children ,it will be different	It will be so difficult to raise them as one cannot get tough on them if they make mistakes and might not be fair to them	
RH8			
RH9		It's a big responsibility and whenever they need to punish them it will be more of an abuse rather than a part of a normal upbringing	
RH10			

Appendix G5: Theme 5: Access to governmental fertility centre

Sub theme1: Shift from private to government

Sub theme 2: High expectations accessing government fertility clinics

Theme 5: Access to governmental fertility centre		
Participants	**Sub theme1: Shift from private clinics to government clinics**	**Sub theme 2: High expectations accessing tertiary governmental clinics**
SQUH1		She was excited to start treatment in SQUH because of its good reputation
SQUH2	The regional hospital lacked the experience and the advanced treatment options which made her attend the university hospital	She considered herself lucky to have got an appointment to be treated in SQUH
SQUH 3		She heard a lot of good things about the clinic in SQUH and was hoping to get pregnant although she was a bit worried to discover something more complicated with her condition

		other than what she has been diagnosed with in private
SQUH4	She opted to stop her follow ups in private clinics as she could not see any progress in her condition plus she no longer could afford the treatment cost	
SQUH5	She has been followed up in the regional hospital and was not satisfied with the received treatment	
SQUH6		She knew that SQUH is a prestigious hospital and has good reputation which has encouraged her to attend the clinic, she was a bit concerned to be diagnosed with a new problem but was glad not to have any other issues
SQUH7		
SQUH8		
SQUH9		She got advice from her sister who has been treated in the clinic and she was excited to deal with professional physicians
SQUH10		
RH1		
RH2	She has been fishing for treatment from one private clinic to another and has travelled abroad too but with no benefit	She was excited to start treatment in government as she has been told it has the best fertility treatment, but was a bit afraid at the same time to be diagnosed with an incurable disorder about her infertility
RH3		She had hope to get pregnant following up in SQUH as she heard that it is an advanced clinic
RH4		She found it way better than the other private clinics she visited and free of charge and was glad they have clearly explained her case as she thought she might have a nasty disease
RH5	She went to many private clinics and wasted her time and money with no success	She is very optimistic with the treatment as IUI is available and unlike in the private clinics ,it is free
RH6	She has spent a lot of money in private clinics with no positive outcome	She was happy to find an advanced treatment with no additional costs and good professional staff, she has also heard many successful pregnancy stories from people attended this clinic

RH7	She has always thought private fertility clinics are better than the government ones and thus spent a lot of money to attend them but she found that she was wrong	She was very excited to start treatment in RH as she heard many successful pregnancy stories with the presence of qualified fertility physicians
RH8	She was burdened with the costs in private clinics and was not happy with the treatment plan given to her there	She was very pleased to start treatment in RH of what she heard about the qualified physicians ,treatment options and all are free of charge
RH9	She believes she was not lucky with treatment in private clinics	She was very happy to start treatment in RH as its one of the advanced fertility clinics in the country and she has waited for 3 month for her first appointment but was pleased to see the clinic and staff to be better than what she expected
RH10	In private fertility centres the attention is on the profit not on the treatment or patient's benefit	She was very optimistic knowing the availability of different treatment options for free and comparable to that in private clinics and she has hope to conceive as it is a professional clinic where doctors in it also run their own well reputable private fertility clinics

Appendix G6:Theme 6: Communication with HCPs

Sub-theme1: Lack of information about medical condition and clinical procedures

Sub-theme2: Language barrier

Sub-theme 3: Nurses' limited role

Sub-theme 4: Gender barrier

Sub-theme 5: Short consultation time

Theme 6 : Communication with HCPs					
Participants	**Sub-theme1: Lack of information about medical**	**Sub-theme2: Language barrier**	**Sub-theme 3: Nurses' limited role**	**Sub-theme 4:Gender barrier**	**Sub-theme 5: Short consultation time**

	condition and clinical procedures				
SQUH1	Participant was confused about the nature of the cysts she has as different doctors told her different things about them	She could not discuss or ask questions as she cannot speak English with the expatriate doctor	The nurses have limited role in the clinic and thus have got less pressure, therefore they are easier to spend time with	She accepts the non-Arabic female physicians as they can get a nurse to translate but she cannot accept the presence of a male physician in fertility clinic	It is easier to deal with nurses as doctors are normally busy seeing a big load of patients
SQUH2	Information given in clinic is very limited ,no one has explained the reason of pregnancy delay and the nature of lab test results		She was very comfortable to deal with an Omani nurse who understands the sensitivity of infertility issue and dealt with her confidentially	She accepts the presence of a male physician but she agrees that there will always be communication barriers	
SQUH3		All what she understood from the doctor is to get her previous medical records as the doctor was speaking in English	A nurse told her that she is for a CT scan during the admission while she did not know what a CT scan is and the nurses did not explain it to either		
SQUH4	Both treatment plan and nature of radiological		She was happy with a particular Omani nurse who	The endocrinologist was a male physician and she was	

	procedures were not explained nor discussed clearly with her, she was also unhappy to be treated in a rude way by one of the endocrine doctors she has been referred to from GYN clinic		was very helpful and cheerful to her, although in general she feels nurses are more friendly with patients, they have a very marginal role in the clinic	embarrased by his questions about her menstrual period and did not feel comfortable to communicate with him	
SQUH5					
SQUH6					
SQUH7	She got used to go and do her own research about the treatment she is on as she do not expect to get the full information from the healthcare providers		Nurses have got more time to spend with patients compared to doctors but their role in the clinic is very limited		The received informatio n during the consultatio n is limited due to the big number of patients who need to be seen in the clinic
SQUH8	She was not given a clear treatment plan and all what they kept telling her in each appointment is to lose weight without giving a clear plan to do so	She doesn't feel comfortable dealing with a non-Arabic speaking doctors as she cannot understand everything they say and sometimes she feels they are making fun of patients, moreover the translating nurse is not	She feels more close to Omani nurses compared to expatriate ones as they belong to the same culture and can understand better what patients go through	She does not feel comfortable to deal with male doctors as she feels they are so rigid in their communicati on and do not have sympathy with patients, there is a barrier to discuss about their reproductive issues freely	She was more happy to have met the senior doctor during her first visit where she has received clear informatio n but in her follow up visits she was disappoint ed to be

		always available to help in communication		with a physician of the opposite gender	seen by junior doctors who rushed the consultation due to the crowded clinic
SQUH9		Language barrier does exist as she cannot speak English and nurses are not always around to translate	Nurses have got more time with patients than doctors who see so many patients every day		doctors see so many patients and it is difficult for them to spend enough time with patients during the consultation
SQUH10			The physician is the one who gives instructions and convey test results and they do almost everything		
RH1	She was not very clear about the nature of the her disease and whether it is the only reason preventing the pregnancy, she has only been told that it is a chronic disease				
RH2					
RH3	The treatment				

	plan was not discussed with her and she was not clear about it, she was also upset and felt she has been treated in a rude way when the doctor told her “You are still a new bride why did you come to seek treatment?”				
RH4		She gets confused dealing with the non-Arabic speaking doctors as nurses are not always free to help in translation			
RH5	Communication with patients is not consistent, some doctors do talk and explain, others do not. She had to use the internet to understand a procedure she was about to go through as she had a wrong understanding about it initially				

RH6	Reason of pregnancy delay was not explained and she was only asked to get her husband's semen test result ,which left her confused			The presence of a trainee male nurse during her second visit restricted and affected her discussion with her treating doctor	
RH7	She was confused and was not given a clear explanation of the nature of her problem	She could not understand the given prescription from the non-Arabic speaking physician			
RH8	She goes back and search the internet to know more about the procedures and the medications she is being given		Nurses are more involved with pregnant women than with infertile patients		
RH9	She was a receiver in setting the treatment plan and was more of instructed to adhere to the plan rather than asked about her opinion				
RH10	"The physician did not talk to me ...she only said what is my problem and said that she will try IUI two times with me and	She wanted to discuss her treatment plan with the physician but she could not as she is a non-Arabic speaker. One she was			She was upset as she has waited for long hours in the waiting area but the physician

	if it did not work she will refer me to do IVF", the medical procedure was not explained to her and she relied on her relative's experience where she gave her wrong information, she also emphasized on the importance of communicati on as the doctor did not pay attention and was calling her with another patient's name which she described as a form of neglect	asked to go for a radiological test in the radiology department where she could nott communicate with the non-Arabic nurses			was in a hurry to finish the consultatio n in 10 minutes and did not give her the attention she wanted

Appendix G7:Theme 7: Professional emotional support

Sub-theme 1: Lack of professional emotional support

Sub-theme 2: HCP's emotional support is a physician's personal choice

Sub-theme 3: The need for emotional support

Access to health care service **Theme 7: Professional emotional support**			
Participants	**Sub-theme 1: Lack of professional emotional support**	**Sub-theme 2: Emotional support is a HCP's personal choice**	**Sub-theme 3: The need for emotional support**
SQUH1	She wished to find emotional support and encouragement but unfortunately she got nothing but the same words about following the treatment plan in each appointment, in her opinion the busy clinics and the pressure on doctors do not help them focus on these aspects unlike nurses who are closer to patients. In addition she will be more encouraged to open up if this conversation is started by the doctor		She was frustrated from HCP's attention to be only on the medical cause and its treatment and that she would not discuss her emotions even if she wanted to until she is given the chance to do so
SQUH2	From what she has noticed HCPs do not normally communicate a lot with patients it is more of a treatment plan to help them conceive		She expressed how doctors only focus on the organic cause of infertility and emotions would be tackled only if patient starts the discussion She suffered going through the treatment where she started with the pills and injections and then did IUI for 3 times and were all failed attempts until she ended up with a complication and got hospitalized and had a moment where she wanted to give up and quit treatment

SQUH3	She is one of the few patients who prefers not to be asked about her feelings as it makes her feel embarrassed		
SQUH4	She is annoyed by the many instructions they have to follow during the treatment and the lack of attention to emotions, she believes the crowded clinic contributes to this		All what she get from doctors are instructions to do tests and take medications and no sympathy at all
SQUH5		She talked about a particular physician who she was more comfortable with as she always considers her emotional status	She encountered a physician who paid attention to her feelings and that has helped her tremendously in opening up and discussing things she never thought she was able to discuss
SQUH6	She noticed that due to clinic's crowdedness, doctors do not pay attention to details of patients' emotions unlike nurses who meet them frequently for investigations and which allows them to have a better rapport with	"But for the psychological support I think that it depends on the physician herself and her personality"	She gets more sympathy and support form nurses compared to doctors who are always in a hurry and cannot pay attention to patient's emotional wellbeing
SQUH7			She had to take many pills for long time and started to experience side effects that she could not bear and had to stop the medications by herself as she could not bear the stress
SQUH8	The emotional support is limited due to the large number of patients attending the clinic		She would love to open up with physicians about her emotions but she does not get the chance as she believes the crowdedness

			of patients does not help doctors to allow for these discussions
SQUH9	She wishes to talk about her emotions but she needs the physician to start this conversation		She expressed her willingness to talk about her emotions but she needs the doctor to start this discussion
SQUH10	She was treated nicely but not asked frankly about her emotions, for her she would not mind to be asked but she thinks not all patients might like it, as for some emotions are considered a private thing which they do not like to share with others		She wishes that HCPs would give more attention to the emotional aspect during the treatment process. She mentioned how some patients might not feel very comfortable to share their feelings but she would not mind She experienced many side effects from fertility medications like nausea, vomiting and fatigue along with mood swings from the hormonal therapy that she could not continue and had to take a break before starting the next cycle
RH1	No one asked her about her emotional status and she thinks this is because of the crowded clinic ,the focus on is mainly on the medical side of treatment, for her she would not mind not to be asked about her emotions as she wants them to focus on her organic disorder and help her get pregnant		
RH2	She did not reveal her emotions because no one asked her about it and was only asked about her medical		Although this participant was against to be asked about her emotions during consultation she expressed her desperate need to this support when she had a

	issues, she thinks this might be due to topic's sensitivity and the limited consultation time. she does not like to talk about her emotions as it hurts her and it makes her feel inferior to others		miscarriage but was disappointed that she could not find it
RH3			Getting asked about feelings during the consultation would help her vent the negative emotions she keeps in from the constant social pressure and will help her feel better and will help HCPs to better understand their patients' wishes and needs
RH4	She did not get any emotional support from the medical team and she did not expect to get any as their focus is on the medical causes and she believe that showing her emotions will be useless as no one would care		She was regular on treatment despite it has increased her weight so much she gets frustrated not to have any support or encouragement from her physicians
RH5	She would open up about her emotions only if she was given the chance but so far no one did, she said once a nurse told her "All the best" before injecting her with the medicine and it made a big difference to her psychologically		She believes in the importance of having a psychological support in the clinic as it makes a big difference according to her experience and she would engage in it if she is given the chance to She is fed up from treatment and the frequent appointments with no success and feels like she is a burden on her husband to drive her a long distance to the hospital, sometimes she

			thinks of giving up but her husband continues to be by her side
RH6	She felt the doctor was nice to her and sympathizing with her condition but no one directly asked about her feelings and she thinks it is mainly due to the big load of patients in the clinic		She feels receiving emotional support is very important to give her hope in continuing treatment, she does not show her emotions anymore as she used to as she was not getting a satisfactory response from HCPs
RH7	she thinks doctors focus on treating the medical cause only although emotions are important too, in her opinion it is better to get emotional support from a professional who understands the medical condition of the patients	Emotional support was always offered to her by a particular physician which made her make sure to only be seen by her during her visits	She met a physician who gave good attention to her condition and her feelings and she wishes to receive the same from others as well as it helps make her more comfortable. She believes her feelings are at equal importance to her medical condition treatment. It is better to get this support from professionals rather than from people who know nothing about your condition She is fed up with all the pills and injections and the repetitive blood tests she has to do
RH8	She thinks doctors might avoid this discussion intentionally due to topic's sensitivity and as they do not want to embarrass their patients	Generally no one checked her emotions except for a physician who was mentioned by another patient who did offer emotional support	She refers to particular physician who always checks her emotions and help her to overcome her stress
RH9			She would like to be given more attention psychologically as she believes it will help her accept and continue the treatment ,she talked about a previous experience

			where she wanted this support the most to start a new treatment but was disappointed not to receive any
RH10	Compared to the private clinic no one paid attention to her feelings in the government fertility clinic and no one is giving hope ,she thinks it might be from the overcrowded clinic and she would like to be reassured and talked to by healthcare providers		She can see the need to have emotional support like what she found in private clinics but could not get the same in government hospitals She is tired and concerned from the multiple injections she takes and wanted to discuss this with her physician but the rush during the consultation did not allow her to discuss this

Appendix G8: Theme 8: Experience with fertility care service and HCPs

Sub theme1: Lack of continuity of care

Sub theme 2: Lack of experience among HCPs

Sub theme 3: Gaps in service and clinic settings

Access to healthcare service **Theme 8 Experience with fertility care service and HCPs**			
participants	**Sub-theme1: Lack of continuity of care**	**Sub-theme 2: Lack of experience among HCPs**	**Sub-theme 3: Gaps in clinic set up**
SQUH1	It is confusing for her to be treated by different doctors and she believes they can follow the set plan by the senior doctor but still they cannot get to know the patient well	She was referred to a dietician but was not satisfied with her management plan ,she expected to receive meals planner but she did not and the dietician lacked the motivational skills needed to help patients lose weight	More treatment options should be available for women with infertility, communication should be enhanced in terms of following up with the same doctor and getting more explanation about treatment plan and their medical condition
SQUH2	She feels it is a chaos to see a different doctor at each visit		She has noticed nurses call patients' names loudly in the waiting area and then they specify the name of the clinic and not everyone likes people to know what they are getting treated for. She believes that the psychological status of patients play an important role to make treatment successful and this is ignored most often by HCPs
SQUH3			
SQUH4	She was so surprised during her second visit to meet a new doctor who took tremendous time to trace her plan and was confused with what tests she has done so far		
SQUH5	Once she saw a Sudanese doctor		Clinics are usually very crowded and they wait for a

	another day an Omani doctor and on another day an Indian doctor and it is confusing to her as she needs to repeat her medical history so many times		very long time to see the doctor, it might take them the entire day and it is difficult if they are coming from far places
SQUH6	Following up with different doctors creates confusion and it is more likely for mistakes to occur ,once they were about to start her a medication that she has finished already ,not all patients are aware of the treatment they are taking and might just follow the doctor's prescription		The long waiting hours to see the doctor is frustrating, especially with the walk in patients who have no scheduled appointments, in addition no privacy is given for husbands to give semen sample as there is no special room for this and they use end up using the hospital's toilets which many find it inappropriate
SQUH7	She prefers to see the same physician who will understand her better and know her journey better		She hopes to have a psychologist in the clinic where she can vent her feelings
SQUH8	She started her treatment with a senior doctor who she was very comfortable with but then she started to be followed up by other junior doctors in her subsequent visits which annoyed her	She is not being encouraged by the dietician as she tells her the same thing in each appointment and does not encourage her to lose ,she is not looking forward to her next appointment with her, she also was not comfortable to deal with the junior doctors as they cannot make decisions by themselves and take long time to	"I feel that an appointment each three months is too wide, and the presence of a psychologist is vital in fertility clinic"

		consult their seniors which wastes the consultation time and make patients question their competence	
SQUH9	Seeing different doctors make them rely on the medical notes of their colleagues ,which might not always be complete and clear	Junior, less qualified fertility doctors rely on the set plan by their seniors which they struggle to follow at times	It's very difficult to get an appointment to be treated in the fertility clinic and it took me a very long time to get my first appointment"
SQUH10	She is more comfortable to follow up with the same doctor who knows her case well and does not need to ask so many questions all over again or spend big time of the consultation reading about her condition and looking up for her tests' results	The junior doctors usually consult their seniors before taking any treatment decisions which affects patient's confidence in these doctors	Physicians should be trained on how to deal with psychological status of patients going through infertility to help them adhere to the difficult treatment regimen and help them have hope
RH1			Long intervals between appointment and crowded clinics
RH2			Treatment should be more robust including IVF
RH3			The treatment in fertility along with services should be more advanced, one example is to have IVF service
RH4	At each visit she sees a different physician but she prefers to see the same one		No financial support for IVF, while she thinks couples should be supported at least for one trial. More scan rooms are needed in the clinic
RH5	What annoys her the most is she sees a different physician each time and she has to repeat her medical	She was seen by a senior doctor in her first appointment and by a junior doctor in her second	IVF should start being supported for patients and more attention should be paid to the psychological aspects of treatment, communication with patients

	history all over to them	appointment where she has noticed the difference in the experience	should be stepped up and more explanation of procedures should be available
RH6	She met a doctor in her first appointment and was very comfortable with her but then she could not find her in her second appointment which made her disappointed	She believed the doctor she saw in the second visit lacked the experience compared to the one she saw in her first visit to fertility clinic	More attention should be paid to privacy especially with patients' medical tests ,location of scan room and there should be a private room for men to collect semen fluid for analysis, separate waiting area should be there for pregnant and not mix them with infertile women
RH7	She sees a different doctor each time she attends the clinic and repeats everything to them, sometimes she gets confused about the many pills she is taking and cannot remember when being asked ,which irritates the care providers		Long waiting time between appointments, more scan rooms are required as doctors usually try to manage two patients at the same time, one in the clinic and the other one in the scan room and they rush with both
RH8	She refuses to see a different doctor each time and when that happened she refused and insisted to see the same one she saw before	She refuses to see other than the senior doctor as she believes she is the expert one and she also cares about the emotional aspect of her patients	There is shortage in fertility care providers which affects the follow up appointments, she also wishes to have more treatment options for women with PCOS and to have IVF
RH9	It is disturbing to see different physicians ,although the treatment plan is noted in the system many doctors will keep ask questions which makes her repeat her story so many times	The junior doctors are less confident in treating fertility patients and need a long time to revise the plan set by their seniors	Privacy should be better maintained in the clinic during consultation, she noticed that patients tend to open the door during consultation to drop result or appointment papers which interferes with privacy, and she wishes from HCPs to pay more attention to patients' emotions

RH10			Patients are annoyed by the quick and short consultation time compared to the long waiting to get an appointment and the long waiting time in the clinic to see the doctor on the appointment day

Appendix H: Healthcare providers' perceptions of the care in fertility clinics

Appendix H1: Information sheet

Title of Study: Healthcare providers' perception of the care in fertility clinics

Name of Researcher(s): Hana ALSumri, Dr.Manpreet Bains, Dr.Lisa Szatkowski

We would like to invite you to take part in our research study. Before you decide we would like you to understand why the research is being done and what it would involve for you. The principal researcher will go through the information sheet with you and answer any questions you have. Talk to others about the study if you wish. Ask us if there is anything that is not clear.

What is the purpose of the study?

This study aims to explore the nature of the healthcare services delivered in fertility clinics. It also aims to have a better understanding of the gaps in care, particularly the extent to which emotional and physical needs of treated women are being met. This will help physicians pay more attention to women's psychological wellbeing during consultations and will help make recommendations for interventions to better support women in this group.

Why have I been invited?

You are being invited to take part because you are a healthcare provider in an infertility clinic. We are inviting 20 health care providers (gynaecologists and nurses) to take part.

Do I have to take part?

It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and 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 agree to take part we will arrange a time to carry out an informal interview when convenient for you. Interviews can be carried out in a private room in the clinic, your office, at your home or somewhere of your choice; you can choose which suits you best. Before you start, the researcher will explain what will happen and if you are still happy to take part you will need to sign a consent form. The interview will begin by understanding your professional role, the nature of the care offered in fertility clinics, how emotional aspects of patients are addressed and the obstacles in care delivery, finally it will end up by exploring your views of how fertility care can be improved. The interview should not take longer than 45 minutes. A voice recorder will be used to record the interview so that the researcher asking the questions does not have to take notes.

What are the possible disadvantages /advantages of taking part?

Whilst there are no foreseeable disadvantages of taking part, we cannot promise that the project will help you personally, but your views and experiences with the services in fertility clinic may help us to understand and identify ways in which quality of consultations could be improved in the future.

What if there is a problem?

If you have a concern about any aspect of this study, you should ask to speak to the researcher who will do her best to answer your questions. The researcher contact details are given at the end of this information sheet. If you remain unhappy and wish to complain formally, you should then contact the Research Ethics Committee Administrator, c/o Sultan Qaboos University(SQU), College of Medicine and Health Sciences. E-mail: mrec@squ.edu.om.Telephone Number:24143427 or Ministry of Health ethical committee ,E-mail dr.h.a.alharthi@gmail.com, Telephone Number:24599688

Will my taking part in the study be kept confidential?

We will follow ethical practice and all information about you will be handled in confidence.

If you join the study, some parts of the data collected for the study will be looked at by authorised persons from the University of Nottingham who are supervising the research. They may also be looked at by a person from the University of Nottingham for translation purposes. All will have a duty of confidentiality to you as a research participant and we will do our best to meet this duty.

All information collected is strictly confidential and any personal information will be deleted from interview transcripts. You will be assigned a unique code that will not identify you in any way. Quotes used in any reports or publications will not

identify you in any way. The voice recordings will be kept securely by the researcher conducting this study, on a password-protected computer.

Your personal data (e-mail/address, telephone number) will be kept for one year after the end of the study so that we are able to contact you about the findings of the study *and possible follow-up studies* (unless you advise us that you do not wish to be contacted). All other data (research data) will be kept securely for 7 years at the University of Nottingham/UK backup servers. After this time your data will be disposed of securely. During this time all precautions will be taken by all those involved to maintain your confidentiality, only members of the research team will have access to your personal data.

What will happen if I don't want to carry on with the study?

Your participation is voluntary and you are free to withdraw at any time, without giving any reason. However, any interview data collected prior to withdrawal may still be used in our analysis.

What will happen to the results of the research study?

The voice recordings from the interviews will be analysed by the research team to see what opinions the group had about the topics discussed. The results may be presented in scientific journals and at conferences. If you would like to receive a summary of the results please let us know, however please bear in mind that this may be some time after your participation as the results have to be analysed.

Who is organising and funding the research?

This research is being conducted as part of a PhD degree of the principal researcher from the University of Nottingham/UK and is funded by Sultan Qaboos University.

Who has reviewed the study?

The Research Ethics Committee at Sultan Qaboos University and Ministry of Health has reviewed this study and approved it.

Further information and contact details

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Thank you for reading this information sheet and considering taking part in this project.
Please keep a copy of the information sheet.

Appendix H2: Consent Form

CONSENT FORM

Title of Study: Healthcare providers' perception of the care in fertility clinics

REC ref: MREC 1377 (SQUH)/14122016(RH)

Name of Researcher: Dr Hana AlSumri

Name of Participant: **Please initial**

1. I confirm that I have read and understand the information sheet for the above study and have had the opportunity to ask questions. ☐
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason. I understand that should I withdraw then the information collected so far cannot be erased and that this information may still be used in the project analysis. ☐
3. I understand that relevant sections of my data collected in the study may be looked at by the research group and by other responsible individuals for monitoring and audit purposes. I give permission for these individuals to have access to these records and to collect, store, analyse and publish information obtained from my participation in this study. I understand that my personal details will be kept confidential. ☐
4. I understand that the interview will be audio recorded using a digital recorder and that anonymous direct quotes from the interview may be used in the study reports. ☐
5. I understand that information about me recorded during the study will be kept in a secure database. If the data is transferred it will be made anonymous. Data will be kept for 7 years after the study has ended and then securely destroyed. ☐
6. I agree to take part in the above study. ☐

Name of Participant Date Signature

Name of Person taking consent Date Signature

Appendix H3: Interview guide

Study Title: Health care providers' perception of the care in fertility clinics

Name of interviewee: Hana AL Sumri

Interview Guide

Objectives

1. To explore healthcare providers' (HCP) views on the provision of fertility care

2. To consider the extent to which HCPs explore infertile patients' emotional wellbeing.

3. To recommend interventions or care guides for HCPs to enable them to better support infertile patients both physically and emotionally.

Introduction

- Thank them for their time and participation. Then explain the purpose of the interview in general.
- We would like to hear your views on the healthcare services you offer in fertility clinics and the extent to which emotional support is offered to this group.
- Statement on confidentiality, right to withdraw consent, recording of the interview.

We would like to reassure you that all data you provide will be kept strictly confidential by the research team. The voice recording of this interview and any quotes used in study reports will not identify you in any way. Your participation is

- Check they have read the information sheet and reiterate main points prior to completing the consent form
- Ask if the participant has any questions before starting the interview.
- Check still happy to take part and that consent form has been signed

A) Job role and first appointment

1. Can you briefly describe your job role?

- unpick the nature of clinics i.e. how many they run each week, typically how many patients do they see
- How many are new and how many are follow ups?
- How much time do they allocate to each appointment and does this differ depending on whether they are new/follow up

2. How long have you been in your current role?

3. Can you tell me how patients end up in your clinic?

- Pathway of referral

4. Can you talk me through what the first appointment in the clinic usually involves?

- Probe around what information is given to patients (what info do they also get from patients)
- Any medical tests being conducted, and treatment plan?
- How much do they involve patients in this?

5. How do patients seem during this first appointment?

- What information they come in with? e.g other peoples' experiences, trust in medical team, pressure to conceive from family/society?...etc.

4. From you experience, what are patients' common concerns when they come to the infertility clinics?

B) Follow up appointments and fertility care

1. What happens after the first appointment?

- When is the follow up appointment? Do they see same physician/care giver?
- How are they arranged?
- What further investigations are arranged? (are these in the same clinic? who does them?)

2. Talk me through how normally procedures are arranged and done?

- Who gives all the information
- How do they get prepared for procedures
- Who conveys any results
- What support offered for them to go through all this?

3. What are the steps followed in your clinic to achieve optimal care?

- F/u with same care providers, establishing rapport, privacy, clinic's environment..etc.
- Medical, psychological, social**…**

5. How do patients respond to the treatment process?

- From possible outcomes, medications, procedures/tests

C) Addressing emotional needs

1. To what extent do you touch upon patients' emotional wellbeing during medical consultations?

- Probe around when do they normally check this? First appointment or in f/u?
- Do they address this for all patients? And what determines this?

2. How comfortable are you asking patients about their emotional wellbeing?

- **can you describe how you broach the subject?**

3. How do you manage visibly distressed patients?

- Can you remember any incidents where you had emotionally distressed patients? And how did you go about it?

D) Psychological support

1. What are the available support services for patients who require them?

2. How are patients referred to the service?

3. How do you decide whether a patient should be referred to this service?

- What does the support service involve? Is there any communication between yourselves here in the fertility clinic with this service?
- To what extent do you follow-up patients' emotional wellbeing?

4. What do you think of these services?

5. What do patients think of these services?

E) Gaps and improvements

1. What are your thoughts on integrating psychological support as part of the routine follow up process in fertility clinics?

2. From your point of view what are the challenges you face in running infertility clinics?

3. How do you think the quality of fertility care can be improved?

4-Based on your experience how do you compare patients with PCOS and infertility to other infertile women

F) Closing remarks

- **Is there anything else you want to add?**

-Re-assure about confidentiality

-Thank participants for their time

Healthcare provider's characteristics

-Gender:

-Nationality:

-Medical role: -Gynecologist - Fertility clinic Nurse

-Clinic location: - SQUH - RH

Appendix I : Health care providers' perceptions of the offered care in fertility clinics

Appendix I1: Theme1: Receiving patients in fertility clinics

Subtheme1: Access to fertility clinics

Subtheme2: Nature of fertility clinic

Theme1: Receiving patients in fertility clinics **Subtheme1: Access to fertility clinics**		
		Prior treatment experience
Hospital1A	Because it is a tertiary canter patient need to be referred to be given an appointment. Referrals come from health centres (HCs) country wide, private clinics and hospitals but also from other clinics inside the hospitals itself	
Hospital1B	They receive referrals mainly from government polyclinics or other regional hospitals but not from primary HCs so referrals are more filtered before they reach to them. Many patients come with high expectations due to hospital's good reputation. This impression is from the experience of other people who have been treated in it	
Hospital1C	Aa a tertiary hospital access is obtained through referrals from all over Oman. Patients struggle to get access in terms of the long time it takes for them to get their appointment, however most of them are happy to start treatment as it is a highly specialized fertility centre	
Hopsital1D	Hospital only accept patients through referral system	
Hospital1E	The bulk of patients come through referrals from local HCs and some from private clinics	

Hospital1F	Access to fertility clinics could be either by internal or external referral pathways	
Hospital1G	In a tertiary centre the fertility clinic is accessed by getting referred from either government clinics or the private ones	
Hospital1H	Most patients access the clinic either as fresh referrals from their regional hospitals, private clinics or other hospital's clinics	Patients trust the tertiary fertility centres more compared to the other places they have visited and come with the hope and excitement to conceive
Hospital1I	People access through referrals from HCs, private clinics or internal referrals from other clinics in the hospitals itself. Patients wait for long time to get appointment. People communicate to HCPs about the experience of other women who have been treated in the same hospital	
Hospital1J	Because it is a tertiary centre, patient's access only by referral system, all referrals usually get screened before cases are accepted to be treated. Due to the high volume, patients wait for long to get their first appointment. However patients are normally excited to get the chance to be treated in a well reputed government hospital and for free so for them it is worth the wait	
Hopspital2A	Patients get referred from the primary HCs if they meet the criteria for infertility	Many who are sent thorough the primary HCs would have had the basic work up investigations along with husband's semen analysis test done
Hospital2B	Patients access tertiary centre through referral system. Most patients are very optimistic to start treatment in government based on other peoples' recommendations about hospital's reputation ,however a small percentage have lost hope in conceiving and come for a second opinion	
Hospital2C		

Hospital2D	Patients access through referrals from both HCs and private sector. Patients are normally excited to start treatment due to hospitals good reputation in treating such cases. Patients normally look for a specific physician to be followed with based on other patient's experience	
Hopsital2E	After patient is being seen in local HCs and investigated, woman will be referred to the tertiary centre if she is the cause of infertility but if there is a male factor he will be referred to another hospital. Referrals are from catchment area but also from all over the country. Patients in our society usually get affected from what they hear about other people's experience with fertility treatment and it determines their decision to start treatment	
Hospital2F	Patients access through referrals from various sources but they wait for 3-5 months to get their first appointment due to the high volume of patients	
Hopsital2G	Patients get to fertility clinics from local HCs, private clinics or other hospitals clinics. Patients access with the expectation to receive the same treatment they heard about from friends and family	Some patients would have been worked up elsewhere while a small percentage would not be and are having a first exposure in the tertiary clinics
Hospital2H	Most patients get referred from local HCs and many from private clinics	Most patients would have been worked up already and might have started treatment as well but they shift to government as they cannot afford the fertility treatment expenses anymore
Hopsital2I	The load is big on tertiary centres as they get referrals from all over the country, especially for challenging cases like PCOS or those with complications due to fertility treatment like ovarian hyper stimulation syndrome	

Hospital2J	Patients get referred mainly from primary HCs after primary work up is being done then they get referred if they meet the infertility criteria, as fertility treatment is only available in tertiary centres. Doctors usually step up the treatment options as patients wait for long (2-6months)to get the first appointment and they are normally excited to start the treatment from the experts	Usually patients would have roamed around and visited many private centres and traditional healers with failed attempts to conceive so they access tertiary centres anxious but hopeful

Theme1: Receiving patients in fertility clinics **Subtheme2: Nature of fertility clinic**		
	Clinic's schedule and routine	**Nature of the first appointment**
Hospital1A	Fertility clinics are run twice a week, each clinic will have up to 5 new cases and 10-12 follow ups. The time allocated for patients varies and it depends on each case's needs, but generally more time is needed for the new cases	In the first visit a detailed history will be taken from the woman along with husband's history without his presence and any semen analysis that has done will be looked at, then series of blood tests and scans will be carried out. A patient will be given an appointment after 2-3 months to review the investigation results and decide on a treatment plan
Hospital1B	It should be 3 new cases and 5 follow ups but due the big number of the patients in the waiting list they overbook patients to accommodate a larger number	
Hospital1C	There might be no more than 5 new cases but they take up to 45 minutes for a full history to be taken from them and investigations, while the follow up cases might take 15-30 minutes	From the first visit and through the obtained history of the couple the physician will do further physical examination and scans from which she can come up with a list of differential diagnosis that gets shortened after the

		results of the investigation are ready
Hopsital1D	Total number of patients booked per clinic do not exceed 15,where 4-5 are new cases and rest are follow ups, the time is given in the system as 10 min per patient but normally they exceed that especially for fresh cases that might take up to 30-45 min, moreover many walk in patients would come for their follow ups that are related to specific days of their cycle	The first visit the woman will be asked about her medical history including her marital history and the duration she has been trying to conceive and any treatment she has tried before then blood tests and scans including swabs will be performed. patient will be given another appointment to check the results of the previous tests and decide if further tests are required before commencing the treatment
Hospital1E	There are 4-5 new cases per clinic and around 12-13 are follow ups, clinics are run twice a week. New cases might require 30-40 min for detailed history taking and scans as well as lengthy discussion to decide on treatment plan	The medical history obtained from the patient along with the physical examination and primary test results will help physician draw a conclusion and put a treatment plan
Hospital1F	There are 4-5 new cases per clinic and 10-12 as follow ups, time varies according to patients' needs but would expect most often new cases to consume more time	As the patient approaches the clinic the medical history and physical examination will be completed and a number of tests and scans will be done, then a primary plan will be set for the patient and the nature of the treatment will be disclosed as some patients might come from far places and need to know about the visits required
Hospital1G	Two specialized doctors will run fertility clinics twice a week with their team doctors where in each clinic 10-15 patients are seen from which 4-5 are new cases. New cases will normally take longer time compared to those coming for follow ups	In the first visit patient's medical history is very essential and a detailed history will be taken to try and rule pot some of the differential diagnosis, after the physical examination a basic work up of hormonal blood tests ,reproductive organs scans and swabs will

		help guide to the definite diagnosis and therefore setting a treatment plan
Hospital1H	Consultants run fertility clinics twice a week, and they see around 15 patients, where around 5 are new and rest are follow ups but more patients come as a walk in on a daily basis for scan. Consultation time is 15-20 min for new cases and around 10 min for follow ups	The first appointment involves detailed history taking including any previous treatment, plus thorough physical examination and basic investigations including blood tests, swabs and ultrasound scan and a primary treatment plan
Hospital1I	Around 20-30 minutes are given to the maximum of 5 new cases while around 10-15 is allocated to follow up cases whom are around 10 per clinic. the clinics are twice a week but daily walk in cases are seen as well who do come for follicular study	Planning for treatment will be only after the obtaining the history along with the results of all the blood tests and the report of the ultrasound scan and the vaginal swab which all together will give a physician a better picture of what they are dealing with
Hospital1J	Physicians have two fertility clinics per week where they see between 15-20 patients and about 5 of those are new cases where they need more time and attention	For the first visit the couple should present together to allow the physician take a detailed medical history, but the way the culture here, men don not attend fertility clinics and their history and investigations are obtained from their wives. Details on women's medical and surgical history will be documented. Later hormonal blood tests, ultrasound scans of reproductive organs along with vaginal swabs will be done
Hopspital2A	Fertility patients visit the clinic daily for follicular study, but the clinic itself runs twice a week with majority as follow up patients and 4-5 new cases. New cases take longer time due to full history taking and examinations, however	Initially a complete history is taken from the patient then she will be scanned to check her ovaries mainly for presence of cysts as it is a common problem and vaginal swabs will be also taken to look for infections and hormonal blood tests will be ordered, then

	follow ups take shorter consultation time	patient will be given an appointment in the radiology department to do the HSG scan to check the patency of her tubes. When all the results are ready a treatment plan will be set.
Hospital2B	Around 15 patients walk in to the clinic on a daily basis with no appointment to do the follicular scan, but among the booked ones there are around 4 new and 10 follow ups. This leads to the big load of patients to be handled by HCPs. New cases normally consume more time during the consultation compared to the follow ups.	The routine in the first appointment is to have vitals checked including patients BMI and then full history taking and basic blood tests, ultrasound scan and vaginal swabs
Hospital2C	Two fertility clinics per week and in each around 20 patients are seen. 6 patients will be new and rest are follow up cases. New cases take long time especially if they are seen by junior doctors who will need to present them to their seniors to agree on a management plan.	Full history of the woman is documented and blood tests and scans will be ordered and further appointment in radiology department will be scheduled to examine her fallopian tubes prior to starting the treatment
Hospital2D	The clinic gets loaded with booked and walk in patients, the booked cases are up to 20 with 5-6 of them being new cases. More time is given to new cases	When a woman comes for her first visit history of couple will be taken from the woman, then ovary scan will be done on the same day at the clinic and hormonal blood tests will be ordered as well
Hopsital2E	Around 15 patients are booked to be seen by fertility physicians however due to the walk in patients coming for scan numbers can be up to 30 patients a day, this puts so much pressure on HCPs who try to see them all.	The first visit will include enquiring about patient's medical, surgical and family histories, transvaginal ultrasound and swabs taken to look for genital infections. A second appointment will be scheduled as soon as possible to review the results ,make a diagnosis and discuss treatment plan

Hospital2F	New to follow up cases are 6:20 and the clinics are twice a week but patients walk in daily to do their scans. Follow up cases consume less time in consultation	In the first visit to the fertility clinic the physician reviews patient's medical history and any previous medications she has taken and check whether she has been diagnosed with the reason behind her infertility. Then a number of tests and scans will be ordered for her to allow the physician come up with a management plan
Hopsital2G	Clinics are run twice a week but follicular scans are done daily, normally there is a big load of patients on clinic's day reaching up to 25-23 cases among them 10-12 new cases	In the first visit more time is given for history taking, although no enough time to take that in detail which includes medical, surgical and any previous fertility treatment taken as it is common for patients to have been seen in private clinics.
Hospital2H	Every Tuesday and Thursday booked fertility cases get seen in the clinic. On each day there would be up to 20 patients apart from the walked in cases. Among those 20 around 4-5 patients are new cases that take up till 20-30 min consultation time while follow up cases take from 10-15 min	During the first visit patients' medical, family and surgical histories are obtained, history of the husband will also be taken from the wife as males do not normally come to the clinic. Basic tests and scans are carried out in the clinic but checking for tube patency requires imaging in radiology department and usually its busy and no slots available until 2-3 months
Hopsital2I	In fertility clinics they see 6 new cases and around 12 follow ups including the walk in patients. New cases might take up to 45 minutes including the examination and basic work up	They assess patients through medical history, complete physical examination including vaginal scans and swabs. Then husband's history will be taken from the wife and depending on previous tests done outside the physician will decide whether to do the tube patency test before treatment or not

Hospital2J	Fertility clinics are run twice a week with around 12-15 patients among which 5-6 are new cases. The allocated time is between 15-20 min for the news ones and around 10 for the follow ups. The physician feels the consultation time is very short	Ideally the first appointment should involve the couple but in Oman due to cultural constraints the husband normally does not attend the clinic and his history is obtained from his wife including the semen analysis test that normally is done in a private clinic. Further clinical history of the woman is obtained along with blood tests and scans. In the second appointment when all results are ready a treatment plan will be agreed on

Appendix I2: Theme 2: Communication between HCPs and patients during the consultation and treatment process

Subtheme1: Role of HCP in the treatment process

Subtheme2: Role of patients in the treatment process

Theme 2:Communication between HCPs and patients during the consultation and treatment process **Subtheme1:Role of HCPs in the treatment process**		
		Doctor-patient communication
Hospital1A	As a specialist nurse she is responsible to filter patients and distribute them on different doctors, she also explains to them the procedures and their nature and the steps required from them to go through them, she also takes part in arranging and doing procedures like IUI. Moreover having a sub-speciality in psychiatry she is able to assess	Patients do not get to follow up with the same physicians and junior doctors rely on plan set by team's consultant in carrying out the management. Furthermore among the challenges is patient's low comprehension of instructions that make them call constantly the reception to ask about appointment and procedures

	patients psychologically if needed and advice for psychiatry referrals, she also authorized to counsel patients if they open up to her	
Hospital1B	As a staff nurse and according to her job description she is not entitled to convey patients results nor explain the procedures as she lacks the experience to do so ,she can refer patients with queries either to the doctor or the speciality nurse	This physician has noticed that patients struggle to keep up with treatment plan as it is very dense and it is either the stress or their educational level that do not help them to grasp the information but she also believes that verbal instructions are not the best and leaflets should be available for them
Hospital1C	Conveying results is exclusively done by doctors but speciality nurses do play a bigger role compared to staff nurses, in explaining the procedures and performing some of them if required	Patients get overloaded with fertility management plan and sometimes it is difficult for them to keep track and doctors do use writing to help patients remember. Being a junior doctor she rotates among different teams and do not get to follow the same patients and will rely on documented progress plan to commence the treatment
Hopsital1D	Staff nurses follow doctor's advice and help patients through the clinic and with their appointment however any further explanation is done only by the fertility nurse or they have to go back to the doctor	Junior doctors would rely on documented plan by their seniors to carry out the management to these patients as they lack the proper experience in fertility being general Ob/GYN doctors
Hospital1E	Its 99.9% down to the doctor to communicate with patients about treatment plan, test results including those of the husband, the speciality nurse might contribute in this but just with doctor's supervision	The time limitation is a barrier to exchange information with the patients and HCPs try to cope
Hospital1F	The physicians convey test results to patients and more tasks are given to the fertility nurse compared to staff nurses	Patients normally are given all the information orally and if they are seen by junior doctors then these doctors must follow the treatment plan set by their seniors and clarify with them any ambiguity in plan
Hospital1G	Doctors decide on management but fertility nurse helps a lot in arranging the required investigations and she might also take history from patients to calculate the dates of her menstrual period and book scans	In fertility management and due to the nature of rotating medical teams it is very difficult to keep up with patients progress and they rely on computerized information to continue with them their management which is not ideal

	and injections accordingly, she might also remind or ask doctors to order certain tests based on each case as she is more expert and knowledgeable compared to staff nurses	
Hospital1H	Physicians have a greater role in the clinic compared to nurses. It is down to the doctors to convey test results and explain the clinical procedures to patients. However compared to staff nurses, speciality nurse plays a bigger role in the clinic, she carries procedures like IUI and explains it to patients, and being an Omani nurse she gets close to patients and might offer counselling if required. Despite the role of speciality nurse there is only one available per clinic's day, and they cannot cover all consultation rooms on that day	Doctors do arrange for investigations and they may use pamphlets that help patients understand the procedures however time is limited to exchange information with patients. Another factor might affect the rapport and communication is the changing of physicians within the medical team, so patient might not get to see the same doctor at different visits
Hospital1I	The staff nurses have more of a logistic role to guide patients through different procedure rooms and arrange patients' appointments according to the treatment plan, but doctors are in full charge	Physicians always rotate between clinics and do not get to see the same patients and this affects rapport building and patient's satisfaction. Moreover patients are normally burdened with fertility management information and time limit does not help further explanation or counselling
Hospital1J	The major role in the clinic is to doctors to set the plan, explain it and conduct the investigations. When it comes to convey test results it is also done by doctors, fertility nurses might trace results and if there are any abnormal results to be acted upon then she will just let the doctor know about it to call the patient and discuss it	Speciality nurse help in the communication barrier between patients and expatriate physicians, leaflets are not available which would help patients comprehend the information better as it's difficult to digest all the information if it is given orally. Moreover a barrier to patients satisfaction is the lack of continuity of care
Hopspital2A	Staff nurses play a marginal role in the clinic, they are more as assistants to doctors and are most often not authorized to convey results not to explain procedures to patients. They are not trained to work in fertility clinics so whenever they need to	Language barrier does exist with non-Arabic speaking physicians and it affects the exchange of information, therefore might require the attendance of Omani nurses to translate. On the other hand the reliance is mainly on verbal explanation to procedures. Patient

	explain to patients they only say what they hear form doctors most often	also lack continuity of care in term of not seeing the same doctor in their visits. Mainly the plan is set by a consultant, then junior team doctors will follow the documented plan
Hospital2B	Staff nurses are required to give appointments to patients and help them through procedures and measure their vitals but all the consultation ,explanation and procedures are done by doctors only	Language barrier does not help to ease the communication and therefore the patient's understanding of their medical problem and the treatment plan including the nature of the procedures, thus patients might go back to the Omani nurses for further explanation. The time constraint does not allow patients to understand the plan fully and they might go back and ask the nurses about it as everything is done quickly due to clinic's load and explanation is only communicated verbally
Hospital2C	Non-specialized nurses have a very limited role in the clinic where they assist doctors in procedures like pap smear and IUI but cannot do them by themselves as they are not trained to do so, however speciality nurses might get more involved in doing the procedures and explaining to patients	Patients always complain as they cannot see the same physician at their visits to the clinic and attending the non-Arabic speaking physicians is also a barrier in their communication with the doctors and for it they go back to the Omani nurses for further explanation
Hospital2D	The staff nurses are not allowed to convey test results to patients nor do the clinic's procedures and their task is limited to check patients vitals, appointments and might assist during IUI procedures	HCPs rely on oral explanation of management plan and procedures
Hopsital2E	Nurses beside their help to doctors to carry out procedures they might give intramuscular injections to patients and make sure they understand the management plan especially regarding the days to follow up for tests and procedures however they are not authorized to give them test results even if they were normal	The illustration in clinic to patients is usually done orally ,there is an Atlas available that doctors might use at times to aid in explanation, but patients are usually educated and like to search in the net about additional information
Hospital2F	Explanation of management plan and procedures are all done by doctors	Non –Arabic speaking physicians might struggle to communicate with patients and therefore will need Omani nurse's assistance to translate

		during the consultation. The physician usually relies on drawing for explanation as there are no Arabic language leaflets available for patients to look at. In this doctor's opinion fertility patients should only be seen by specialist doctors and not the junior ones to get the optimal level of care
Hopsital2G	The doctor is the one who sets the treatment plan and thus is required to explain everything to the patient, staff nurses are helpers and can guide patients through the clinic and give them the additional instructions to be followed before they come for procedures	Unavailability of illustration leaflets in Arabic halts patient's understanding to the procedures. The impression is that patient is more satisfied with treatment outcome no matter the way and the details of it unless patient herself shows the interest to know more about the procedure then they will give more attention in explanation
Hospital2H		There are some leaflets to help patients know more about the procedures but some doctors prefer to use drawing to explain to patients. Language barrier also exists and patients go to Omani nurses to understand what has been said and discussed ,some of them will try to search for the information using the internet but they might end up with the wrong materials
Hopsital2I	Due to the shortage of nurses in the clinic some doctors do not have assisting nurses assigned to them and therefore they have to do everything by themselves which puts so much pressure on them	For this physician she always refers back to an illustrated Atlas to help explain procedures to her patients and she believes in the importance of continuity of care and seeing the same physician as it helps build rapport and therefore better treatment outcome
Hospital2J	Staff nurses are helpers in the clinic regarding patients flow in and out of the clinic and they assist in procedures, but speciality nurse's role is more important however there are shortage of them compared to the big number of patients	The absence of leaflets in the clinic does not help doctors explain clearly to patients about their problem and the procedures they are about to go through especially that the consultation time is limited to do so. Moreover seeing the same patients in each visit helps create a stronger bond and rapport with patients although this is not possible all the time

Theme 2:Communication between HCPs and patients during the consultation and treatment process Subtheme2:Role of patients in the treatment process	
Hospital1A	Patients IQ level and stress level play an important role in their understanding of the treatment plan and therefore their involvement in setting it
Hospital1B	Patient's role in treatment is believed to be through following instructions and completing the required tests and taking medications as instructed and they have to report for any side effects. Most patients adhere well to treatment as they know the importance of it to help them conceive
Hospital1C	Patients involvement in treatment plan is seen to get their consent to go through the tests and procedures, Omani patients are patient and very compliant with treatment with the hope to conceive
Hopsital1D	She believes no plan should be set without patients involvement however many do contribute in plan as they have been exposed to these options before in private and their education level also plays a role. On the other hand most patients are very compliant with treatment as it is associated with having a child, so they are so motivated
Hospital1E	Patient's role is to cooperate with physicians in terms of giving a complete and honest history and follow the required investigations and show up on days of appointment and to take medications as instructed. After probing she related patient's compliance and involvement in setting the plan to their duration of infertility, the longer the duration of infertility the more vocal the patients would be in setting the plan
Hospital1F	Omani patients are good believers and accept things well and they know what options are available so they do not challenge the plan set by doctors most often
Hospital1G	The duty of patients is to follow the treatment plan and instructions and take medications on time. Patients normally do not read about treatment options and are not aware of them to discuss or influence the plan and they value each visit after a long gap and attend them with full compliance
Hospital1H	The role of a patients with PCOS is to comply with management plan especially regarding their weight reduction. Patients involvement in plan setting depends on their age and duration of infertility, older patients and those who have been infertile for longer time are more anxious and look for faster results so they influence the plan more compared to younger patients with shorter duration of infertility who will trust the doctor's plan and are ready to go through stepwise plan. In general patients are seen to accept the plan set especially if they cannot afford IVF
Hospital1I	Patients involvement in plan is always there but mainly patients know about hospitals' reputation and that it is research based so they normally trust the opinion of physicians in setting the plan ,especially if they cannot afford IVF they have no hope but to continue following in the hospital
Hospital1J	Patient's level of education and curiosity will make them ask and inquire more about the plan and options for treatment and this is the minority, the majority will just follow the doctor's instructions as they just want to get pregnant and they would adhere well to treatment and their appointments
Hopspital2A	Patients do trust the consultants available due to their reputation and do not argue much about plan, many follow and adhere strictly to treatment as they wait

	for long to access these tertiary centres and they are desperate to carry a pregnancy. Omani patients have a big trust on doctors compared to nurses
Hospital2B	It is very rare to see patients who stop attending the clinic after the long wait to access it except few who pull out if they fail to conceive or are left with IVF option which is not available
Hospital2C	Patients understanding and education level plays role in their involvement in setting the treatment plan
Hospital2D	From her experience older patients who are approaching their 40s and have been exposed to many treatment options are more vocal when it comes to treatment options as they fear to approach menopause and wants to utilise the most advanced treatment options
Hopsital2E	Patients in the clinic are very compliant and adhere to treatment most often without negotiations, they trust the treating physicians and are desperate to conceive and have no way out especially with the faced social pressure
Hospital2F	Some doctors believe that patients role is to strictly follow the plan set be doctors to help it succeed while other believe patient's education, external knowledge about fertility treatment and previous exposure to fertility treatment help them assess the logic of the set plan. However among the ones who challenge the plan this latter can be tailored to her convenience
Hopsital2G	Patients do trust doctors in these centres and therefore do not contribute much in setting the plan, however older patients with long duration of fertility are more challenging compared to the younger ones who are being exposed to treatment for the first time
Hospital2H	From her experience very few patients discuss the treatment plan and this might mainly be due to their literacy about fertility treatment options as they rely to get the information from physicians only
Hopsital2I	For her she always likes to give options for her patients to choose from and she can feel patients involvement is more if they are older in age and have tried so many other treatment options
Hospital2J	From her experience she noticed patients access to government clinics after multiple trials to conceive in private therefore doctors do not waste time by repeating the lower levels of treatment plan and go straight to the most advanced technique which is IUI and therefore patients are left with no options to choose from. On the other hand patients want to conceive and they adhere very well to treatment and arrange their situation to be compliant with treatment schedule

Appendix I3:Theme3: Perceptions of patient's psychological wellbeing

Sub-theme1: Patient's social concerns and expectations

Sub-theme 2: Patents' medical concerns about fertility treatment

Sub-theme3: Patients' medical concerns specific to PCOS

Theme3: Perceptions of patient's psychological wellbeing

	Sub-theme 1: Patient's social concerns and expectations	**Sub-theme 2: Patents' medical concerns about fertility treatment**	**Sub-theme 3: Patients' medical concerns specific to PCOS**
Hospital1A	Patients do communicate to HCPs about the pressure from their in laws about the pregnancy delay and how they push them to seek treatment early and their hints around them their husbands need to remarry which stresses them more. Patients come with different levels of depression. From her experience women try to hide that they seek fertility treatment and do not want to meet people who they might know in the clinic who can find out about their infertility	Patients get stressed from the long time required for investigations to be completed especially that some are related to specific days of the period and this might coincide with public holidays or weekends where the clinic is closed. They also get disappointed after finding out IVF is not available	Women with PCOS get delayed in starting fertility treatment mainly due to being unable to reduce weight ,they also start seeking fertility treatment early after marriage as they know about their anovulation prior to marriage and anticipate their need for medical intervention to conceive
Hospital1B	They see depressed patients very often and they are stressed from both social pressure and treatment failures. Women are blamed often and their husbands do not cooperate if are called to be investigated as it is a shame for men to be labelled infertile in the society	Cases approach at an old age and not much time is left for them to take long in fertility treatment so they get very stressed and anxious especially knowing there is no IVF when they cannot afford it	
Hospital1C	Women are always blamed for infertility and therefore are expected to be tested first and husband is always considered	Women come and are rushing the treatment with the hope to conceive fast	Women with PCOS are more prone to ovarian hyper stimulation syndrome as a reaction to fertility

	not to be the reason behind the delay, in addition in this society stress and anxiety escalate once 5-6 months pass from marriage without pregnancy and this is due to the social pressure on women most often		treatment that might be very critical and require ICU admission so they are more difficult to treat otherwise the rest of the symptoms are believed not to be so disturbing to them
Hopsital1D	Most patients are concerned about the delay others are hiding their treatment from their husbands not to give them a reason to remarry, moreover many husbands do not respond if are asked to be investigated	Patients get devastated when they consume all available means to conceive but fail and are left for IVF and because it is not offered in government they stress about handling its expanses	
Hospital1E	Women come with depression especially going through many failed attempts to conceive elsewhere and being pressurized by their in laws. Male infertility is challenging as many do not accept it socially	Disappointment is apparent when patients find IVF is not offered in government while others might be more conservative when IUI is offered as they fear samples to get mixed, other concerns like multiple gestations are seen as something good while it should be feared as it threatens their pregnancy	She thinks emotionally women with PCOS are not very different from other patients but medically they are more vulnerable to fertility treatment complications
Hospital1F	Social pressure is apparent among most of the women	Patients who try IVF but fail to conceive come to government clinics and try lower levels of treatment options as they are trying to hold on hope, others are	Patients with PCOS might need dietary advice most often or are referred to bariatric surgeons for weight reduction purposes. Moreover once they get pregnant more

		worried to try IUI as it is perceived stigmatizing to get pregnant through unnatural means others fear the mixing up of semen samples during the procedure	attention should be given to them early and late during their pregnancy as they are prone to comorbidities and complications
Hospital1G	The social pressure is intense on these women and hints are always there around husband to remarry , in this country men are always fine and blame is on women for infertility and many men refuse to cooperate in investigations which delays the treatment, they prefer to remarry to prove their fertility than to be investigated and to be the ones with the defect	Patients get disappointed from the big time gaps between investigations which delays the treatment process and patients usually rush and require the maximum doses to cut short the time. They usually do not care about the possible side effects even when told about multiple gestations as they consider it as an advantage rather that a complication. On the other hand many get frustrated knowing IVF is not available nor being supported financially to them as it used to be	Special attention and care is given to patients with PCOS as they are normally accepted to be seen early in fertility clinics even if they have not completed the 1 year of marriage without conceiving. They are believed to be more depressed going through the symptoms of masculinization early since puberty at time when they should feel their femininity, this is further compounded by their struggle to carry a pregnancy
Hospital1H	Men are normally not seen in fertility clinics due to cultural constraints and the belief that the fault is always from women. Women do communicate the social pressure on them to conceive and the stress and anxiety due to that	Patients usually come to tertiary centres exhausted from the repeated tests and trials in private and they usually are in a hurry to conceive, the long wait between appointments stresses them and	Women with PCOS are more challenging as they struggle with weight reduction and many find it very difficult to reduce weight despite being involved in weight reduction programs.

		they get disappointed from the failed trials going through the many ovulation cycles. Money is not an issue as treatment is offered for free but the obstacle when they are left to do IVF as it is not available in the current setting	Emotionally they seem to be more disturbed as they have been in this treatment journey of their condition since adulthood and they suffer from other symptoms such as acne, hirsutism and infertility just adds to their suffering. Moreover they are more prone to have complications from fertility treatment compared to other infertile women
Hospital1I	Being an expatriate physician she was shocked to see how couples seek fertility treatment early after marriage and found it to be due to the tremendous social pressure on them		
Hospital1J	Infertility is considered a big issue in this part of the word as it has a social dimension to it and pregnancy is expected soon after marriage and women's identity is linked to her fertility, women are always blamed and men infertility is socially unacceptable and it is the mother in law who will start looking for a bride for her son	Women attending fertility clinic will normally have a level of desperation and most are annoyed from the long time between visits but it is out of hand as some investigations will have a long queue of waiting patients and are necessary to be performed prior to commencing the fertility treatment. Moreover patients come with expectation to receive IVF but get disappointed	It is more challenging to deal with women with PCOS as they have weight issues and are difficult to respond to fertility treatment

		knowing it is not provided	
Hopspital2A	Women do communicate about the pressure from family and friends and the continuous questioning about their pregnancy delay and the threat of husband to remarry for children	People who access after being treated in private for long are more emotionally drained and hopeless but try to look for hope, others who are younger and have not been exposed much to treatment are very excited and hopeful instead	Women with PCOS always struggle with weight issues and are referred most often to dieticians to help them reduce weight as treatment is very difficult without weight reduction
Hospital2B		Some patients are anxious about certain procedures ,whether they are painful or not others get worried and hesitant about IUI as they fear from semen samples to get mixed while others believe it is prohibited in our religion	Patients with PCOS struggle with weight reduction and they get desperate as it is very difficult to lose weight, they also suffer from other symptoms like acne and increase body hair growth
Hospital2C	Patients are psychologically affected from infertility even those who are not the only wives to their husbands and despite husband might have children from his other wives, these patients are also young and would want to be mothers, many do concern about their age and worry to end up with no children at an older age	Many patient do not desire repetition of the tests and investigations they have done in private ,and some come with the hope to receive IVF but get disappointed knowing it is not available. People now are accepting IVF and IUI more as they used to fear from samples getting mixed or for them to be prohibited in Islam	If women with PCOS struggle a lot with weight reduction and they are obese or morbidly obese then they might be referred to surgeons instead of dieticians to save them time

Hospital2D	Women come to fertility clinics with a lot of stress especially of husband to remarry	Women usually are anxious and cannot handle further delays in treatment especially if they are old as they fear their chances to conceive get less with aging	Weight reduction among women with PCOS is the most challenging among them
Hopsital2E	In our community some women visit fertility clinics secretly as they do not want to be seen by others especially that they are mixed up with pregnant women in the waiting area, patients reveal feelings of depression from social pressure and getting compared with their sisters in laws and be looked at inferiorly for their pregnancy delay. women do fear their husbands to abandoned them and they are always the ones to be blamed	Patient are emotionally drained trying several treatment in private with no successful outcomes, they shift to government due to the high expanses of these treatments in private and they look for any hope but again are afraid of negative outcomes despite this they adhere to treatment as it is their last hope	Women with PCOS barely could lose weight and it is frustrating to them
Hospital2F	Women are very vulnerable in our community to the extent if the man was the reason behind the pregnancy delay women will try to hide it and take up the blame as they know man's fertility is a reflection of his manhood and masculinity and its shameful to be labelled with infertility	Chronic patients have little hope and negative expectations of treatment success as they have gone through a lot earlier, however younger patients are seen to be more optimistic. An additional issue is overweight and obesity which is very common and can be due to depression among some women and	Obesity is common in general among women seeking fertility treatment ,big proportion are with PCOS other might be due to depression from infertility, therefore treatment cannot be commenced before weight reduction so they are sent to dieticians others might need more attention therefore are sent to surgeons, in general

		it makes treatment more challenging	women with PCOS suffer from other comorbidities and its challenging to treat them
Hopsital2G	From her experience women in Oman rush to carry a pregnancy soon after marriage and this is all due the social pressure on them as hints around them for husband to remarry threatens them and make them anxious. Socially any delay in pregnancy must be a sign of a fertility issue and it cannot be perceived as intentional delay of pregnancy.	Despite the young age of women they are normally seen very anxious and stressed and are rushing to complete fertility treatment, many also fear IUI and doubt if it is allowed in Islam as they are also fearing from mixing up the semen samples. In addition women perceive multiple gestation as an advantage and are not aware of the medical consequences	The high BMI among women with PCOS delays their fertility treatment and many get counselled to try and reduce their weight but patients get upset as they do not believe there is a link between high BMI and infertility .Moreover women with PCOS are challenging for the other comorbidities common among them including diabetes and hypertension
Hospital2H	Patients do express the pressure they go through from their families and others even from their husbands who constantly blame them and refuse to be tested	Patients are frustrated from the long wait between appointments especially going through all of it in private before ,moreover the hormonal disturbances they go through due to treatment increases their stress level	When patients with PCOS are advised to reduce weight they do not take the advice seriously and do not follow the dietician's advice and it is challenging to convince them of the importance of weight reduction
Hopsital2I	Mostly they see chronic cases with long duration of infertility who are mostly anxious stressed and depressed and are confused from the pressure and the different advice of	Patients get frustrated starting the treatment especially those coming from far places and need to arrange transports frequently to attend their appointments ,all	Women with PCOS are seen more anxious and more depressed due to weight reduction struggle and all the other comorbidities seen among them and they most often do not respond well

	what to do regarding the delay. Moreover husbands most often do not like to be seen in fertility clinic and it is considered a shame and stigma for them	these contributes to the stress faced going through treatment process	to fertility stimulations which increases the emotional burden on them
Hospital2J	Given the nature of the culture men are afraid to be seen in fertility clinics due to shame and they usually do not attend the consultation as they should and women are always stressed and anxious to conceive as adoption is not an option in the culture and socially women in Oman are expected to carry a pregnancy right after marriage and any delay will always be alarming and no one will think it is part of family planning	Patients are normally excited to start treatment in such tertiary specialized clinic especially after the long wait but also are anxious to conceive	Common issues with women with PCOS is weight and their struggle to reduce it, patients usually are given 6months to one year to try and reach their goal otherwise for those with morbid obesity they usually get referred to gastric surgeons for sleeve gastrectomy surgery. Women with PCOS also struggle with other symptoms which drain them emotionally, moreover they are at higher risk of fertility treatment complications and once they get pregnant they are also more challenging due to other comorbidities during pregnancy such as GDM and PIH

Appendix I4:Theme4: Identifying and addressing emotional wellbeing among patients

Subtheme1: Approaching patients' emotions

Subtheme2: Barriers to approaching patients' emotions

Theme4: Identifying and addressing emotional wellbeing among patients **Subtheme1: Approaching patients' emotions**	
Hospital1A	Providing better services in the clinic, facilitating patients' appointments and trying to fasten their procedures are considered forms of support to these patients, however direct emotional support is given only if patients clearly express their disturbance such as start to cry in clinic
Hospital1B	Emotional support is offered only if patient starts talking about it or expresses it directly
Hospital1C	As a doctor she does not volunteer to ask patients about their emotions but will deal with it accordingly
Hopsital1D	Inquiries about patient psychological status will start if patient decides to withdraw from treatment or visibly shows her distress
Hospital1E	Emotional support is not a routine practice and is offered only if HCPs perceive the need to
Hospital1F	As a specialist she believes offering support to patients should be a routine and should come naturally from HCPs, for her she always checks on that and she believes it is down to physician's nature and personality
Hospital1G	For her she likes to offer support in the subsequent visits rather that during the first visit as she gets to understand the patient better and patient might feel more comfortable, however she might not always get the chance to do this as she might not be the one to see the patient in the following visits due to the rotations of doctors between different teams
Hospital1H	normally patients emotions are approached only if patient is visibly very disturbed and tearful or of she expresses it verbally then more time might be given to her during the consultation to sooth her pain and disturbance
Hospital1I	Physicians are being gentle with patients during history taking and examination and show sympathy and that is an indirect form of support but as a routine they do not offer emotional support although they feel they should practise it, however whenever they perceive the need to from patient's body language or behaviour they will check on it. Moreover seeing the patient repeatedly help physicians build rapport and understand patients better to be able to detect these issues
Hospital1J	She believes that emotional support is always offered by doctor's empathy towards these patients through the use of gentle words ,facilitating treatment options to them and their body language towards

	patient, but then more direct support will be offered if patients visibly and explicitly expresses her emotions
Hopspital2A	Physicians are different there are some who prefers to check routinely on patients' feelings and emotional wellbeing as a personal choice others are not willing to check it on routine basis , some patients are more conservative but they are vulnerable and if given the chance they would express their feelings . Moreover Omani HCPS are usually closer to patients as they belong to the same culture which helps patients to open up about their emotions
Hospital2B	Checking on patients' emotions during consultation is not done as a routine among physicians unless patients start the conversation
Hospital2C	It is difficult to implement psychological support to each patient during the limited consultation time, so it is definitely not a routine practice but physicians might give more attention to patients if they clearly expressed their negative feelings, moreover doctors always sympathize with patients and try to make their appointments more smooth and easy
Hospital2D	Physicians offer emotional support only if patients started the conversation, otherwise they believe giving good explanation about the reason of the pregnancy delay and offering a treatment are ways of supporting this group of patients
Hopsital2E	As a nurse she feels patients get more time to spend with them compared to physicians and they see them more often as they come frequently for tests which help build rapport with them, moreover it is her personality being close to her patients and sensitive to their feelings and struggles and she admits it is a personal behaviour, but for doctors majority will start the conversation of patient's wellbeing only if patients start talking about it
Hospital2F	Patient's emotions are not routinely checked by HCPs even for chronic cases with long duration of infertility but they might approach the topic only if they see visible signs of a low psychological status
Hopsital2G	Physicians do not get into details of women's emotional status unless they feel the need to from patient's behaviour, as patients in this society normally hide their feelings. However these feelings are more apparent when they lose a pregnancy where they definitely show distress and need more support emotionally
Hospital2H	From her nature and experience in the practice it is easy for her to touch patients emotions and get them to express them
Hopsital2I	For this physician she mainly anticipates patients need of emotional support and she uses gentle words if she is about to break a bad news to a patient and she is always connecting pregnancy delay to God's will and use it strongly to calm patient and remind them of God's generosity and destiny to help them get consoled
Hospital2J	For this physician it is her routine to ask patients about their emotional wellbeing especially in the first visit but she is not sure if other physicians are doing it as well

Theme4: Identifying and addressing emotional wellbeing among patients **Subtheme2:Barriers to approaching patients' emotions**		
	Social barriers	**Professional barriers**
Hospital1A	Visiting psychiatry is not very well accepted yet in the community and patients might not go based on the recommendation for the fear of community's reaction and husband's rejection	Being a speciality nurse with special training in psychology she is more qualified in assessing patients emotionally and can better detect negative signs compared to doctors who are less trained and are more focused on treating the medical causes
Hospital1B		
Hospital1C	From her experience women in Oman are very shy and conservative and usually do not like to speak up about their emotions ,they feel embarrassed to be seen attending psychological support and are afraid to be labelled with unpleasant descriptions by the community like being "crazy"	
Hopsital1D		
Hospital1E	Sometimes referring to behavioural medicine is considered as a stigma in this part of the world so HCPs should be careful in attempting this step	The limited time along with the language barrier make it difficult to offer emotional support and the presence of a professional psychologist is necessary to take up this task
Hospital1F		
Hospital1G	It is challenging for some to be referred to receive psychological support as it will add to the perceived stigma from infertility ,many fear that this step might be a good reason for husbands to remarry as they will consider their	Many factors halt offering emotional support including :it is not a standard treatment measure and it largely depends on physician's personality and style,

	wives not only infertile but also mentally ill "crazy"	physicians are less trained to handle this aspect of patient's care and their focus is on the organic cause, language barrier is another factor among expatriate physicians
Hospital1H	When patients are psychologically affected and require referral to psychiatry department they refuse as socially it is stigmatizing to attend psychiatry and they might be labelled as mentally unstable so they avoid it	The time limit for consultation and the language barrier among expatriate physicians do not help them address patients emotional needs
Hospital1I	If there is a need of a professional support it might be offered but if patient is not willing then it cannot be forced on them	The big volume of patients leads to limited consultation time where HCPs barely get enough to focus on the medical side of treatment, a proper psychologist clinic would be a better alternative and more practical with the current setting
Hospital1J		Language barrier ,time constraints, lack of doctors training to provide this support and lack of psychological services in the hospital are obstacles towards touching upon patient emotional wellbeing
Hopspital2A	When asked about their opinion to have a psychologist clinic integrated with fertility clinics she thought some women will not accept it especially if the word "psychologist" is mentioned, as women will be embarrassed and ashamed to be seen attending the service and a word like "social worker" will be more acceptable socially	Language barrier among expatriate physicians will limit their ability to offer emotional support as most often they will need the Omani nurses around to translate, moreover the unavailability of a professional psychologist in the hospital is an additional barrier for support to be offered
Hospital2B	Some patients do not feel it is appropriate to share their feelings with others especially HCPS as it is very personal. In her opinion she thinks patients might not accept the service of psychological support if it becomes part of the fertility clinic as socially visiting a	The big bulk of patients will barely allow the time for consultation and scans to be completed ,but if patients' emotions are routinely checked there will be no time to see the rest

	psychologist will make people think she is mentally unstable ”crazy”	of the scheduled patients for that day
Hospital2C	Offering psychological support through psychologist might be challenging to a group of people who are not yet aware of the role of such support and still believe visiting psychologist is an indication of mental instability and she might be labelled as ”crazy” ,however with more awareness people might accept it especially women are more educated nowadays	
Hospital2D		Time constraint plays a big role in physicians inability to provide the needed emotional support as they see big number of patients that exceeds the ones with a prior booking
Hopsital2E		A policy of allocating more time for patients to be able to be assessed fully did not succeed as there are always the walk in patients to be seen and HCPs end up with limited time for the booked cases, in addition language barrier is present and expatriates find it difficult to communicate and offer support if they want to, she admits that some patients do need a professional emotional support and doctors should pay more attention to this
Hospital2F		
Hopsital2G	She came across a patient who required psychological support the doctor was very careful to introduce the subject to the couple and had to indirectly mention patient’s need for support from another clinic to be able to convince the couple to take up the service	In her opinion many factors act as barriers to offer this support: the limited consultation time, lack of privacy to counsel patients especially on days with big load of patients who keep on knocking on the door and entering to drop papers or results, language barrier and the absence of psychiatrist in the same hospital

Hospital2H	Some doctors believe that due to the nature of the culture women are receiving enough support from their families and therefore are not expecting to receive any from HCPs	Language barrier is not helping patients express their feelings when they are seen by expatriate physicians ,moreover the limited time for consultation is an additional barrier ,on the other hand unavailability of a psychological support in the hospital makes it unfavourable to refer patients to other hospitals.
Hopsital2I	Nowadays social support from woman's family and husband is available and patients might prefer to stick to that compared to receive it from professionals	She believes hospital should invest on an Arabic speaking psychologist with qualification in psychology or train nurses to take up this role
Hospital2J	Women in Oman feel opening up about their emotions is socially unacceptable especially to HCPs fearing to be labelled with mental disease so this is considered a barrier to offer proper support to them	Doctors are illness centred rather than being patient-centred in care and lack the proper training to deal with patents' emotions, based on her training abroad fertility clinics always have a psychologist who can offer emotional support to patients and she believes this should be implemented especially that the hospital lacks behavioural medicine department

Appendix I5: Theme 5: The need for psychological support

Theme 5: The need for psychological support	
Hospital1A	The only support offered to fertility patients is trying to change the system to accommodate them more smoothly, but they are aware patients with primary infertility are depressed and this is increased by starting treatment. They are looking forward to have a dietician and psychologist to support these patients especially those with PCOS who struggle to lose weight
Hospital1B	The support offered to patients is only through improving clinic's set up but patients need to vent their feelings and this is seen frequently in the clinic but no proper place and time are available for this kind of support, the HCPs understand the need of this support by employing a specialist nurse with a background in psychology but due to the high number of following patients she cannot offer this support as needed. Patients go into breakdown finding about their need for IVF as it is not available nor financially supported as it used to be. Having a proper psychologist and dietician will help a lot in providing a holistic approach and therefore patients satisfaction
Hospital1C	Many patients struggle to accept their pregnancy delay especially those chronic cases with many failed pregnancy attempts who sometimes are desperate for support and welcome it if offered, doctors cannot give much of support being out of their experience ,doctors usually believe the psychological status of fertility patients plays a major role in treatment success rates
Hopsital1D	The burden from the lived social and medical experience of these women is so tremendous and what little is offered during consultation is not enough, these patients need better psychological attention to their emotional status
Hospital1E	The need for emotional support is evident but there is very little that can be done given the limited time in the clinic, doctors try through facilitating patients follow up and being gentle in conveying negative results as ways of offering support but they know it is not enough especially for patients with devastating results or loss of precious

	pregnancies. Having a psychologist will lift the burden off doctors' shoulders as patients will have the time, privacy and the professional advice. Patients with PCOS are more depressed from their body image to start with which is compounded by their inability to conceive
Hospital1F	The only way to satisfy infertility patients is try and make their visits more comfortable and smooth but many are mostly anxious, worried and depressed, it will be very helpful to have expert psychological support especially if does not include the treating physicians as they lack time and experience. Patients with PCOS are a big challenge with their slow response rate to fertility treatment and their struggle with weigh reduction
Hospital1G	HCPs are aware of patients psychological status especially going through the stressful fertility treatment but can do very little about it given the big load of patients following up in the clinic and there is a slacken from doctor's side to address these issues including dietary advice which is only given by dieticians to patients with impaired glucose during pregnancy and not to those who need weight reduction especially patients with PCOS who are more affected emotionally from a younger age with the syndrome's masculine symptoms
Hospital1H	The need of psychological support is apparent as women with PCOS will normally struggle to lose weight and get delayed in starting the treatment, moreover many steps have been taken in the clinic to facilitate the follow ups of patients with infertility considering the emotional burden among them, in addition unavailability of the emotional support service increases the need to have it as part of fertility clinic, especially with the burden of going through the extensive fertility treatment, for patients with PCOS they might be in a greater need of emotional support given their struggle with the disease way before marriage
Hospital1I	Many factors play role for patients with fertility to be depressed including the treatment and pressure from family and friends ,the lack of support from HCPs require intervention of psychologist support in the clinic especially rapport building which helps patients to open up to physicians however due to lack of continuity of care rapport with patients is difficult to be achieved
Hospital1J	She believes that hormonal disturbances among women going through fertility treatment and the social pressure and blame on her are a lot to be bared by patients and they need to unburden and talk to someone about it, many patients would feel more comfortable to share feelings with someone outside their social circle which is lacking ,a presence of a psychologist will be very helpful especially most patients will not prefer to visit the psychiatry department as it is culturally stigmatizing and doctors feel it is so complicated to refer patients who just need a psychologist support rather than a psychiatrist. Women with PCOS are always more challenging with weight reduction and then more likely to develop complications from fertility treatment, they also have other comorbidities
Hopspital2A	Fertility patients are drained emotionally going through fertility treatment and its failure, steps are considered in the clinic to ease their sufferings and help fasten their treatment process, women with PCOS mainly struggle with weight reduction and this increases their

	frustration, as a physician she believes patients need to relieve their stress and speak out and thus presence of a psychologist who can give them enough time to express their worries will be very beneficial even for the treatment process
Hospital2B	Patients with infertility will always have a level of depression and need the space to express their feelings and it is difficult to allow this during the limited consultation time, physicians know how burdened they are with the dense treatment plan and show sympathy by trying to see them faster and get more flexible with them, however the hospital lacks psychiatry department which increases the need to have a psychologist in the clinic, women with PCOS are seen more depressed from weight struggles and the other symptoms related to the syndrome and therefore might need more emotional attention
Hospital2C	Depression is common among infertile women and many express the need to talk about it but physicians do not have the time nor the experience to deal with these issues, all what they can offer is to facilitate their treatment journey as possible. Being aware of the extra emotional burden from the treatment, she believes offering professional emotional support will help a lot
Hospital2D	Physicians understand the emotional burden among fertility patients but cannot do much about it, they try to change the clinics set up to make it more comfortable, she believes emotional support should be offered to those who fail after so many attempts to conceive or those who become candidates for IVF but cannot afford it, not to have a psychiatry department in the same hospital makes it essential to provide a psychologist
Hopsital2E	The negative emotions from the social pressure among patients are evident and many require time to express their feelings during the consultation which is not always possible given the current load of patients, moreover patients also suffer from the repetitive tests and visits to fertility clinic and the hormonal effects of the medications and feel relieved to talk to professionals compared to family members. Those with PCOS suffer from the syndromes' symptoms including their increased weight. She believes having a psychologist will be a very successful step and people will accept it
Hospital2F	Patient's emotional status is very crucial during the treatment, HCPs try to provide the support through encouraging words and use of words of hope, however no time is available during consultation for proper counselling, many patients are overweight probably due to depression and do not appreciate the importance of losing weight and need more support to do so, the absence of IVF as treatment modality increases the stress and depression among patients. Moreover the absence of behaviour medicine department in the hospital is challenging and patients will benefit from the presence of a psychologist who is professional and understands the Omani culture and the religion. Patients with PCOS are more challenging with weight issues and other comorbidities and might find emotional support very helpful
Hopsital2G	From her experience some fertility patients need more attention and support as they struggle to accept their infertility and its treatment, a patient who was more relieved and encouraged after being treated from depression is a good example of the need of this support. Women

	with PCOS might suffer more from the other symptoms related to their condition including weight reduction issues
Hospital2H	Patients get emotionally disturbed going through the hormonal changes from fertility treatment which is aggravated by the intensive visits to fertility clinics and treatment failures ,many do communicate the social pressure on them to conceive and therefore offering proper psychological support is believed to be necessary especially to women with PCOS who are more challenged with weight reduction as part of their condition
Hopsital2I	The chronic cases are always depressed and the social pressure increases the burden on them, apart from the few words given to them by HCPs to sympathize with them there is no proper counselling to these women who are in need to vent their feelings, incorporating emotional support will help these women to accept the treatment. Women with PCOS are suffering more from their symptoms including the additional comorbidities among them and the struggle of their weight reduction and thus might be in greater need for this support
Hospital2J	The social pressure on women with infertility warrants the need for emotional support ,this pressure is tremendous and expected in a country where adoption is not the norm, moreover breaking news to patients like their need for IVF despite its unavailability require additional support to help patients cope. In addition women are seen keen to vent their feelings to physicians after building a rapport with them but time constraints don not allow for this, in a hospital where no presence of a psychologist this becomes mandatory. People are more educated nowadays and willing to open up. Moreover patients with PCOS specifically are more emotionally stressed from the symptoms ,comorbidities, weight reduction struggle and being at higher risk even after carrying a pregnancy

Appendix I6:Theme6: Challenges to providing better level of care at clinic's setting

Theme6: Challenges to providing better level of care at clinic's setting	
Hospital1A	More efforts should be made to provide fertility patients with a more satisfying care by allocating a special clinic for them away from pregnant women, allow them to be seen by the same physician, provide a private room for their husbands to provide seminal fluid and to increase the number of scan rooms and IUI rooms
Hospital1B	Infertility patients need more support in terms of increasing the number of specialized physicians and clinics ,provide proper room for collection of seminal fluid for husbands and find solutions to support couples financially to go for IVF
Hospital1C	Patients need to be seen in dedicated fertility clinics away from pregnant women to void the negative influence on them, and they should be emotionally supported by a professional, a dietician is also required for proper diet advice to those who need it. Finally to provide IVF for patients to be able to satisfy this group pf patients
Hopsital1D	In her opinion only highly specialized staff should follow fertility patients and not the junior doctors who rely on consultants' notes to manage the patients attending these clinics
Hospital1E	Additional resources should be invested on fertility clinics to provide them with IVF, dieticians and counsellors also to improve the space and number of scan and IUI rooms and assign more fertility HCPs
Hospital1F	The main obstacle for patients with infertility is the absence of IVF in the government set up which limits the physician's ability to help those who needs it, only if IVF centre is initiated all the other issues regarding clinic's set up will be solved by having a proper fertility

	centre that is a separate body from obstetrics and gynaecology clinics
Hospital1G	Fertility patients do not have separate clinics to be seen in and they are mixed with pregnant women therefore there are limited number of physicians and limited number of rooms allocated for them in the clinic leading to the long waiting time to see the doctor. Moreover the scan room is shared with pregnant women follow ups and so are the IUI procedures which are done on the treatment room that is shared with pregnant women as well. Men have no privacy to provide the semen fluid and therefore avoid it. The clinic is dominated by women which is not ideal as fertility clinics should have both couples following up together for better results. The absence of IVF is a dead end to many couples
Hospital1H	Challenges that face fertility clinic is unavailability of services such as IVF where patient come to a dead end and have to pay out of their pocket for it and most cannot afford it, no professional dietician available to help patients especially those with PCOS to reduce weight as it is a crucial step before commencing fertility treatment, psychological support is essential given the limited time and big load of patients for doctors to offer this support especially to women with PCOS who are in a greater emotional suffering. Further limitations in the clinic's set up is the mixing up between fertility an pregnant women in the same waiting area which might not be appropriate
Hospital1I	Emotional support should be offered to fertility patients, fertility clinics are so crowded and doctors cannot spare time to take care of that aspect, the number of doctors and therefore of fertility clinics should be increased to help accommodate more patients and to give them more time during consultation. In addition unavailability of IVF is an obstacle to those who need it but cannot afford it
Hospital1J	In an ideal setup a fertility centre should be available as population number is growing and more specialists are required in the field ,more advances in the used technologies in treating fertility should be available to patients like IVF with proper couple counselling including a full team of dietitians and counsellors
Hopspital2A	The long waiting period for appointment is due to the high load of fertility patients being referred to the hospital and there are few number of specialised doctors to handle these patients. Moreover unavailability of IVF is a challenge in the service.
Hospital2B	The load of patients is huge and the few numbers of HCPs make it challenging to handle them and thus limited consultation time, additionally husbands might be required to provide semen sample for analysis or IUI procedure and there is no special dedicated place for them where they use the hospital's washroom or they rent a flat nearby the hospital as many cannot provide the sample given the hospital's environment .Moreover the dieticians are not qualified to help patients lose weight which delays the treatment process
Hospital2C	The hospital needs to provide a proper room for men to collect semen sample as many women complain of their husband's

	struggle to provide the sample given the unsuitable environment, the big load of patients requires more physicians. The biggest challenge is the unavailability of IVF to those who need it. More rooms are also needed for IUI procedures and nurses should be trained to get more involved in these procedures and decrease the load on doctors
Hospital2D	Fertility patients should be separated from pregnant women in the waiting area considering their emotional status, private room should be also provided for men to collect the semen sample as no privacy is currently available. Government should help patients go for IVF since they are not providing it for them. Dieticians and psychologists should be part of the fertility clinic to provide a holistic approach in treating these patients
Hopsital2E	The high load of patients requires increasing the number of doctors and thus fertility clinics. IVF is a big challenge to patients as it is not provided nor sponsored, no privacy for men to provide semen sample and many fail to do so which delays the treatment process ,moreover having a dietician should be part of the clinic to help patients access them easily for advice
Hospital2F	There is a big load of patients to be handled by a small number of HCPs which contribute to the delay in appointments and investigations and limited consultation time. The hospital lacks IVF which is an obstacle to patients and HCPs in providing ultimate care, many husband also struggle to provide semen fluid given the current set up of the clinic and lack of privacy. Psychological support is challenging to offer since there is no psychiatry department in the hospital and an external referrals are required
Hopsital2G	The high number of following patients affect the quality of the consultation, the clinic should have a private room for men to give semen samples as many cannot provide it due to lack of privacy, the presence of dieticians and counsellors are very important in fertility clinics and IUI is the maximum that can be offered to patients but many need IVF which is not available
Hospital2H	Being a tertiary centre that accepts referrals from all over the country the load is huge and thus the long waiting time, moreover IVF is a dream for many patients who cannot afford it but it is not provided by government, finally women with PCOS need more attention to their weight struggles and emotional wellbeing
Hopsital2I	Patients always complain about the long periods to get appointments but the load is a lot on HCPs to accommodate the large numbers, women also complain about their husbands not having privacy in providing semen sample. IVF should be at least supported for some patients as it is not available, the presence of dieticians and counsellors in fertility clinics are mandatory especially for the more challenging patients like those with PCOS
Hospital2J	IVF is considered a right for patients with infertility and either it should be available or at least sponsored, moreover dieticians should be qualified to handle patients with high BMI especially those with PCOS with resistant obesity, in addition the emotional support is mandatory to help patients cope and accept treatment. Continuity of care is another challenge where patients struggle to

	build rapport with their doctors by seeing a different one each time, especially that fertility patients are frequently visiting the clinic

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