EXPLORING PATIENT-CENTRED CARE AND HELP-SEEKING BEHAVIOUR AMONG INFERTILE FEMALES IN JEDDAH GOVERNORATE, SAUDI ARABIA: A MIXED METHOD APPROACH

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LIST OF SYMBOLS

&	And
X^2	Chi-square
=	Equal
>	Greater than
≥	Greater than and equal
<	Less than
≤	Less than and equal
n	Number of populations
Ψ	Odds ratio of exposure in cases relative to controls
%	Percent
α	Type I error probability for a two-sided test
β	Type II error probability for a two-sided test

LIST OF ABBREVIATIONS

AMOS	Analysis of Moment Structure
ANOVA	Analysis of Variance
AOR	Adjusted Odds ratio
ART	Assisted Reproductive Technologies
ASRM	American Society for Reproductive Medicine
AVE	Average variance extracted
CBRC	Cross-border reproductive care
CB-SEM	Covariance-based structural equation modelling
CFA	Confirmatory factor analysis
CFI	Comparative fit index
Chi-square/df	The Chi-square value divided by its degrees of freedom
CI	Confidence interval
COSMIN	COnsensus-based Standards for the selection of health Measurement INstruments
COVID-19	Coronavirus disease of 2019
CR	Composite reliability
CVI	Content validity index
df	Degree of freedom
DHS	Demographic Health Survey
EFA	Exploratory factor analysis
FertiQoL	Fertility quality of life
FertiMed	The fertility medication questionnaire
FVI	Face validity index
HSB	Help-seeking behaviour
HTMT	Heterotrait-monotrait ratio
ICSI	Intracytoplasmic sperm injection
I-CVI	Item content validity index
IDI	In-depth interview
I-FVI	Item face validity index
IUI	Intrauterine insemination
IVF	In vitro fertilization
KMO	Kaiser-Meyer-Olkin

M.I.	Modification Indices
MAP	Minimum average partials
MENA	Middle East and North Africa
n	Number
OI	Ovulation induction
PCC	Patient-centred care
PCIC	Patient-centred infertility care
PCIQ-F	Patient-centred infertility questionnaire for female clients
PCQ-Infertility	The Patient-Centred Questionnaire-Infertility
PRISMA-ScR	The preferred reporting items for systematic reviews and meta-analyses the extension for scoping reviews
QPP-IVF	Quality of care from patient's perspective for IVF treatment
RMSEA	The root mean square error of approximation
SAR	Saudi Riyal
S-CVI/Ave	Scale content validity index
SD	Standard deviation
SEM	Structural equation modelling
S-FVI/Ave	Scale face validity index
SPSS	Statistical Package for Social Science software
STROBE	Strengthening the Reporting of Observational Studies in Epidemiology
TLI	Tucker-Lewis index
US	United States
USD	United States Dollar
VIF	Variance inflation factor
WHO	World Health Organization

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MENEROKAI PENJAGAAN BERPUSATKAN PESAKIT DAN TINGKAHLAKU MENDAPATKAN BANTUAN DALAM KALANGAN WANITA DENGAN MASALAH KESUBURAN DI JEDDAH, ARAB SAUDI: SATU PENDEKATAN MENGGUNAKAN KAEDAH CAMPURAN

ABSTRAK

Tesis ini bertujuan untuk meneroka konsep penjagaan kemandulan berpusatkan pesakit (PCIC), membangunkan dan mengesahkan instrumen bagi mengukurnya, dan mengenalpasti hubungan antara PCIC dengan tingkah-laku mendapatkan bantuan (HSB) dalam kalangan wanita Arab yang tidak subur. Ia dijalankan di Jeddah, Arab Saudi dalam tiga fasa bermula dari Januari 2017 sehingga Disember 2022 menggunakan kaedah campuran. Fasa I ialah kajian kualitatif yang meneroka konsep PCIC dalam kalangan wanita tidak subur yang menerima rawatan perubatan dalam tempoh 6 bulan yang lalu. Wanita telah diambil secara prosedur persampelan bertujuan sehingga ketepuan dicapai. Empat belas temu bual mendalam telah dijalankan dan dianalisis dengan analisis tematik induktif. Fasa II ialah kajian validasi untuk membangunkan dan mengesahkan soal selidik ketidaksuburan berpusatkan pesakit untuk pelanggan wanita (PCIQ-F). PCIC-F diformulasi berdasarkan penemuan kajian kualitatif dan semakan literatur. Kajian penerokaan kemudiannya dilakukan ke atas sampel penyelidikan dalam talian yang mudah bagi 201 wanita tidak subur untuk mentakrifkan binaan terpendam PCIQ-F menggunakan Analisa Faktor Penerokaan. Kemudian kajian pengesahan dilakukan ke atas sampel 316 wanita tidak subur untuk menguji sifat psikometrik PCIQ-F dan untuk menghasilkan versi akhir PCIQ-F. Fasa III ialah tinjauan keratan rentas secara dalam talian yang mengkaji hubungan HSB wanita tidak subur dengan tahap PCIC dalam tempoh 6 bulan terakhir melalui analisis regresi logistic dan analisis *path* dalam

struktur kesepadanan model (SEM). Kesan moderasi jenis rawatan kesuburan keatas hubungan ini telah diuji melalui analisa pelbagai kumpulan. Ia menggunakan PCIQ-F dengan tambahan kepada soalan tentang penggunaan serentak rawatan bukan perubatan semasa rawatan perubatan kemandulan. Seramai 466 orang wanita telah dimasukkan. Fasa 1 mengenalpasti sembilan dimensi PCIC yang diterima oleh wanita Arab; kebolehcapaian; meminimumkan kos; sikap dan komunikasi kakitangan; maklumat dan pendidikan; keselesaan fizikal; privasi; kecekapan kakitangan; sokongan psikologi dan emosi; dan kesinambungan dan penyelarasan penjagaan. PCIQ-F mempunyai empat bahagian: pengenalan, ciri latar belakang, PCIC, dan penilaian kualiti keseluruhan. Bahagian PCIC mempunyai 4 domain (24 item): komprehensif penjagaan, komunikasi dan maklumat; pendidikan dan sokongan pesakit; pemerkasaan pesakit; dan keselesaan fizikal. Analisis statistik membuktikan kesahihan dan kebolehpercayaannya. Fasa III mendapati tiada perkaitan yang signifikan antara PCIC dan rawatan bukan perubatan (P=0.078, AOR0.86, 95%CI0.73, 1.02). Walau bagaimanapun, pemerkasaan pesakit dan keselesaan fizikal menunjukkan hubungan yang signifikan, masing-masing *p*=0.023, 0.032 AOR 1.20, 0.83 95%CI 1.02,1.41; 0.71,0.99. Walau bagaimanapun, PCIC, pemerkasaan pesakit dan keselesaan fizikal menunjukkan kesan negatif secara terus keatas bilangan sumber yang dikunjungi bagi kemandulan, dengan masing-masing *p*=0.001 for all, and beta -1.29, -0.534, -0.257, S.E.0.128, 0.071,0.042. Jenis rawatan kemandulan mengurangi hubungkait antara PCIC dan HSB. Kesimpulannya, konsep PCIC dari perspektif wanita Arab merangkumi sembilan dimensi. Berdasarkan dimensi ini, alat yang sah dan boleh dipercayai (PCIQ-F) telah dibangunkan. PCIC mempunyai kesan negatif untuk mendapatkan rawatan bukan perubatan, yang dimoderasikan oleh jenis rawatan. Kami mengesyorkan untuk melaksanakan PCIC di kemudahan kesihatan dan

mengukur pelaksanaannya menggunakan PCIQ-F, yang boleh meningkatkan HSB wanita.

Kata kunci: berpusatkan pesakit, ketidaksuburan, teknik pembiakan berbantu, tingkah laku mencari pertolongan

EXPLORING PATIENT-CENTRED CARE AND HELP-SEEKING BEHAVIOUR AMONG INFERTILE FEMALES IN JEDDAH GOVERNORATE, SAUDI ARABIA: A MIXED METHOD APPROACH

ABSTRACT

This thesis aims to explore the concept of PCIC, to develop and validate an instrument to measure it, and to determine the relationship of PCIC with the help-seeking behaviour (HSB) among Arab infertile women. It was conducted in Jeddah Governorate, Saudi Arabia in three phases from January 2017 to December 2022 using mixed-method approach. Phase I was a qualitative study that explored the concept of PCIC among infertile women who received medical care within the last six months. Women were recruited purposefully until saturation was reached. Fourteen in-depth interviews were conducted and analysed by inductive-deductive thematic analysis. Phase II was a validation study to develop and validate a Patient-Centred Infertility Questionnaire for Female clients (PCIQ-F). PCIC-F was formulated in the light of the results of the qualitative study and literature review. A pilot study was then carried out on an online convenience sample of 201 infertile women to define PCIQ-F latent constructs using exploratory factor analysis. Furthermore, a field study was undertaken on 316 infertile women to test PCIQ-F psychometric properties and to produce the final version. Phase III was a cross-sectional online survey which examined the relationship of HSB with the PCIC during the last six months by logistic regression and path analysis in structural equation modelling. The moderation effect of the type of infertility treatment on this relationship was tested by multi-group analysis. The tool was PCIQ-F with added questions about the concurrent use of non-medical treatment during infertility medical care. A total of 466 women were included. Phase I identified nine PCIC dimensions valued by Arab women; accessibility; minimising costs; staff

attitude and communication; information and education; physical comfort; privacy; staff competence; psychological and emotional support; and continuity and coordination of care. PCIQ-F comprises four sections: introduction, background characteristics, PCIC, and overall quality assessment. PCIC section is divided into four domains (24 items): comprehensiveness of care, communication and information; patient education and support; patient empowerment; and physical comfort. Statistical analysis proved the validity and reliability of PCIQ-F. Phase III found no significant effect of PCIC on seeking non-medical care (p=0.078, AOR 0.86, 95%CI 0.73, 1.02). However, patient empowerment and physical comfort showed a significant effect, p=0.023, 0.032 AOR 1.20, 0.83 95%CI 1.02,1.41; 0.71,0.99, respectively. Furthermore, PCIC, patient empowerment, and physical comfort showed direct negative effect on the number of sources seen for infertility with p=0.001 for all, beta –1.29, -0.534,–0.257, S.E.0.128, 0.071,0.042, respectively. The type of infertility treatment partially moderated the relationship between PCIC and HSB. In conclusion, the concept of PCIC from Arab women's perspectives embraces nine dimensions. Based on these dimensions, a valid and reliable tool (PCIQ-F) was developed. PCIC has a negative effect on seeking non-medical care, which is moderated by the treatment type. We recommend implementing PCIC in health facilities and measuring its implementation using PCIQ-F, which could improve women's HSB.

Keywords: patient-centred, infertility, assisted reproductive techniques, help-seeking behaviour.

CHAPTER 1

INTRODUCTION

1.1 Background

Infertility is a disease, defined by American Society for Reproductive Medicine (ASRM), characterized by the inability to conceive after 12 months of consistent, unprotected intercourse, or as a result of a person's impaired ability to conceive (American Society for Reproductive Medicine (ASRM), 2020). The global estimated prevalence of infertility ranged from 13% to 18% (Cox *et al.*, 2022). The prevalence rate of infertility increased worldwide among all age groups; by 0.37% per year for women and 0.29% per year for men from 1990 to 2017 which was associated with a concomitant increase in age-standardized disability-adjusted life-years of infertility for both genders (Sun *et al.*, 2019).

Male factor is the only cause of infertility in 20 to 30% of cases, female factor in 45 to 58%, combined factors in 40%, and infertility is unexplained in 25 to 28% (Vander Borght and Wyns, 2018). Surprisingly, Arab women who are childless are frequently considered the main cause of infertility, and they were frequently lacking social, financial, and personal support leading to depraved psychosocial consequences (Hamdan, 2016; Ibrahim *et al.*, 2019). Ovulatory dysfunction is the most common aetiology in female infertility, other causes include tubal damage, endometriosis, coital problems, and cervical factor (Vander Borght and Wyns, 2018). Management options of infertility are developing fast including wide variety of agents and techniques (Taylor *et al.*, 2019).

However, it is well known that both genetic and environmental factors can contribute to infertility, which emphasizes the significance of studying infertility within the context of the patients' racial and sociocultural background (Lawrenz *et al.*, 2019).

Knowing that, Middle East infertile couples could get benefit from region-specific counselling and treatment focusing on parental consanguinity, obesity and vitamin D deficiency which are very common contributors in the region (Lawrenz *et al.*, 2019).

The treatment journey of infertile couples is invariably long, full of emotional, psychological, and social traumas (Rooney and Domar, 2018; Pozza *et al.*, 2019; Zurlo *et al.*, 2020). At the end, the rate of achieving child birth after in vitro fertilization (IVF) is varied greatly but estimated to be around 37% with good quality embryos after all the pain and suffers (Adamson *et al.*, 2018).

For such kind of a journey, it is worth to consider all outcomes of infertility management rather than focusing solely on the objective of having a baby. Shreffler et al., (2020) defined a comprehensive concept; fertility-focused assessment and intervention, which empowers couples during their infertility fighting journey with comprehensive assessment and counselling for both medical and non-medical treatment options aiming to improve infertility treatment outcomes and minimize its risks. Knowing that, the provision of infertility care in the broader context of family medicine adds the advantages of covering both the medical and emotional aspects of infertility (Thable *et al.*, 2020).

It is well-known that a desire to have a baby is extremely strong by human nature, but unexpectedly, it was estimated that around 42% of infertile women sought medical care and about 22% underwent medical treatment (Passet-Wittig and Greil, 2021b). The causes are many, but the first thing jumping in our minds as a medical practitioner is simply: Could it be because we did not provide our infertile couples what they need and expect? What if we achieved patient-centred infertility care (PCIC)?

1.2 The global burden of infertility

1.2.1 Prevalence of infertility

Infertility is a public health problem worldwide (CDC, 2022). The total fertility rate, which is defined as the average number of live births per woman, has dropped by 49.4% from 1950 to 2017 which goes more with the increasing infertility rate (Murray and GBD 2017 Population and Fertility Collaborators, 2018). The prevalence of infertility is estimated as one in eight couples worldwide (Cox *et al.*, 2022). However, the burden is higher in low- and middle-income countries which showed the most substantial annual percentage change of infertility rate specifically the Middle East, North Africa, and Latin America (Sun *et al.*, 2019; Withers, 2021).

The prevalence of infertility varied in literature and is difficult to compare due to the lack of consistency in the definitions adopted by the researchers (Jacobson *et al.*, 2018). There are three infertility definitions used commonly in literature; clinical, demographic, and epidemiological (Akhondi *et al.*, 2019; Assaf, 2021). These definitions differ in three aspects. First; the outcome of concern being either failure to achieve live birth (the demographic definition) or to get pregnant (all others). Second; the definition of the period of infertility being either the period of unprotected intercourse (the clinical definition) or of trying for pregnancy (all others). Third; the duration of infertility either 12 months (the clinical), two years (the epidemiological), or five years (the demographic definition). Table 1.1 shows these heterogenous definitions which explained the gross variation in infertility prevalence rate in literature. To clarify more, a study was conducted to compare female infertility prevalence across different definitions (Jacobson *et al.*, 2018; Cox *et al.*, 2022). Jacobson et al. (2018) used a survey covered 11 different definitions of infertility so each participant answered the eleven definition-related questions. It ended up with 11 different prevalence rates of

infertility in the same sample ranged from 6% to 43%. For example; the definition based on "attempting pregnancy" gave a crude prevalence rate of 20% with the duration was set at 12 months vs 11% when extended to 24 months. However, definitions based on "unprotected intercourse" gave higher prevalence rates at the same duration.

Table 1.1 Definitions of infertility in research papers

Terms	Definitions
Clinical	*"a disease* historically defined by the failure to achieve a successful pregnancy after 12 months or more of regular, unprotected sexual intercourse or due to an impairment of a person's capacity to reproduce either as an individual or with her/his partner"* ASRM[*] (ASRM, 2020).
Epidemiological	*"women of reproductive age (15–49 years) at risk of becoming pregnant (not pregnant, sexually active, not using contraception, and not lactating) who report trying unsuccessfully for a pregnancy for 2 years or more."* WHO[**], for monitoring and surveillance (Limiñana-Gras, 2017).
Demographic	failure to achieve pregnancy with a live birth, after at least five years of a consistent union status, lack of contraceptive use, non-lactating and expressing a desire for a child. WHO[**], DHS[***] (Assaf, 2021)

ASRM[*]: American Society for Reproductive Medicine; WHO[**]: World Health Organization; DHS[***]: Demographic Health Survey

1.2.2 Infertility morbidity

At both the individual and societal levels, the harms of infertility are evident. The World Health Organization (WHO) recognized infertility as a public health problem that affects between 48 million couples and 186 million people globally (WHO, 2023). The high infertility prevalence and its possible effect on population growth; the preventable factors of infertility; the dangerous effect of infertility and it's treatment on health; infertility stigma and its consequences; the declaration of reproduction as a human right; and importantly, the presence of public health actions

that could help in controlling the problem of infertility, all justify seriously considering infertility as a public health issue (Mann *et al.*, 2018; CDC, 2022; WHO, 2023).

At the level of infertile couples, infertility is a “disease" and could result in significant morbidity and disability (Zegers-Hochschild *et al.*, 2017; American Society for Reproductive Medicine (ASRM), 2020). Morbidities could be categorized into either complication of the infertility itself which can affect any of the infertile couples or both of them, or complications of infertility treatment includes maternal and perinatal.

Infertility found to be associated with poor marital adjustment, low quality of life, less intercourse satisfaction, partner violence, psychiatric disorders especially anxiety, depression, adjustment disorder with mixed anxiety and depressed mood, eating disorder, obsessive-compulsive symptoms, psychoticism, and substance abuse (Winkelman *et al.*, 2016; Fallahzadeh *et al.*, 2019; Pawar *et al.*, 2019; Yazdi *et al.*, 2020; Wang *et al.*, 2022). Depression levels in patients suffering from infertility was found to be comparable with cancer patients (Rooney and Domar, 2018)

A meta-analysis involved a total 5055 infertile women from thirteen studies to identify the experience of anxiety among infertile women (Kiani *et al.*, 2020). It found the rate of self-reported anxiety among infertile women as 36% with a higher pooled prevalence level in low- and middle-income countries (54%) than high-income countries (25%) (Kiani *et al.*, 2020). Nevertheless, that psychological interventions for women with infertility could reduce anxiety and depression as well as increase pregnancy rate (Rooney and Domar, 2018).

Despite that the advances in infertility management especially assisted reproductive technologies (ART) helped many infertile couples to achieve their dream, these techniques are not without their complications. ART is associated with fetal

complications such as multiple gestation, preterm delivery, small for gestational age, low birth weight infants, intra-uterine death, and perinatal mortality (Ombelet *et al.*, 2016; Sunderam *et al.*, 2019). In addition, severe life-threatening maternal morbidity and mortality associated with ART were reported including severe preeclampsia, severe postpartum haemorrhage, hysterectomy, disseminated intravascular coagulation, acute fatty liver requiring red cell or plasma transfusion, and other morbidities (Dayan *et al.*, 2019; Sabr *et al.*, 2019). Severe ovarian hyperstimulation syndrome affects 1% of IVF patients and could lead to serious illness including renal failure, adult respiratory distress syndrome, ovarian rupture and haemorrhage, and thromboembolic phenomena (Taylor *et al.*, 2019).

Long-term complications affecting children included neurologic morbidity especially attention deficit/hyperactivity disorders, headaches, and sleep disorders up to 18 years of age (Levin *et al.*, 2019).

1.3 Infertility in Arab World

The 22 Arab League nations that are found in Africa and Asia are referred to as the Arab world (World Population Review). These countries are Algeria, Bahrain, Egypt, Iraq, Jordan, Kuwait, Lebanon, Libya, Morocco, Oman, Qatar, Saudi Arabia, Sudan, Syria, Tunisia, the United Arab Emirates, Yemen, Somalia, Djibouti, Mauritania, Comoros, and the State of Palestine (World Population Review). Although Modern Standard Arabic is the official language, many other Arabic dialects are also widely used (Guellil *et al.*, 2021). The majorities of Arab World population are Muslims (World Population Review).

It is crucial to take social and cultural contexts into account when discussing a subject pertaining to client perspective. Although Middle East countries have a

similarity, they lack the language bond as three of the Middle east countries are non-Arab; Turkey, Iran and Israel (TeachMideast, 2023). Applying results from client's perspective on other countries require a similarity in language as well. So, Arab World is better fit the scope of the current study. In the same vein, literature showed that Arab populations preferences and health-seeking behaviour greatly influenced by their culture and religion (Bertran *et al.*, 2017; Arabiat *et al.*, 2021).

The prevalence of infertility in Arab World is difficult to be estimated due to lack of proper registration and sound researches in many Arab countries. International Committee for Monitoring Assisted Reproductive Technology report in 2011 presented data from 65 countries only four of them are Arab; Egypt, Lebanon, Morocco, and Tunisia (Adamson *et al.*, 2018). An attempt to estimate infertility prevalence in Middle East and Africa (MENA) by meta-analysis was conducted in 2017 (Eldib and Tashani, 2018). The majority of the retrieved papers (seven out of nine) were Iran which is non-Arab country. In brief, one paper found in Saudi Arabia, and the second was the analysis of survey data by WHO included four Arab from the 190 countries; Egypt, Morocco, Jordan, and Yemen. The prevalence was difficult to estimate due to heterogeneity of the studies. Generally, countries which was included in the demographic health survey of WHO, and thus used the demographic definition, showed very high prevalence rate at 33% in comparison with other world region, keeping in consideration that the demographic definition used five years duration of childlessness which tends to underestimate the prevalence rate as clarified above.

A meta-analysis of infertility in Sudan showed that the pooled prevalence of overall infertility was 13%, primary infertility 65%, and secondary infertility 35% (Abdullah *et al.*, 2021). Regarding the causes of infertility; 41% were due to female factor (ovulatory factors, 36%; polycystic ovary syndrome, 38%), 27% due to male

factor (azoospermia (37%), oligozoospermia (30%), and asthenozoospermia (30%)), 16% combined factors, and 17% were unexplained infertility (Abdullah *et al.*, 2021).

A study to identify the prevalence of infertility was conducted in Arar city, Saudi Arabia including women attended the outpatient and inpatient department in Maternity and Children Hospital (Alamri, 2020). The prevalence of infertility was 65%;20% were primary and 80% were secondary infertility. The most frequent reported causes of infertility among the 65% infertile patients were ovulatory dysfunction in 25%, polycystic ovarian syndrome in 22%, tubal factor in 7%, endometriosis in 3%, and uterine fibroid 3% as well.

Regarding the aetiology of infertility in MENA region, male factor was found in 25% of infertile couples, while female factor in 40%–58% (Eldib and Tashani, 2018). However, a more recent study in Qatar uncovered other potential causes of infertility and found that genetic abnormalities like hyperhomocysteinemia, thalassemia, were the cause of 5–10 % of infertility cases due to high prevalence of consanguineous marriage (54%), varicocele was responsible of 30% of infertility in men, and chromosomal abnormalities causing male oligospermia or azoospermia found in 11% of Qatari infertile men (Zauner and Girardi, 2020).

Other common causes were hypovitaminosis D, polycystic ovarian syndrome, obesity, hypothyroidism, sexually transmitted diseases and certain vaginal/endometrial microbiomes, diabetes which affects 17% of Qatari population, cardiovascular diseases and hypertension, asthma (20% of Qatari population), and lifestyle and environmental factors (Zauner and Girardi, 2020).

Interestingly, a recent systematic review was conducted to identify the genetic epidemiology of male infertility in Arab countries (Okashah *et al.*, 2022). It retrieved data from nine Arab countries; Tunisia, Algeria, Morocco, Syria, Jordan, Yemen, Iraq,

Egypt and Lebanon. The review showed 25 genes responsible of male infertility, including 89 variants, 42% of them were unique to Arab patients and azoospermia was the most frequently phenotype identified (Okashah *et al.*, 2022).

Infertile men who were evaluated at a Male Infertility Unit in Qatar between January 2012 and August 2015 were the subject of a retrospective study on the results of semen analysis (Elbardisi *et al.*, 2018). The outcomes were divided into MENA region patients (n = 8799) and non-MENA patients (n = 5093) based on the country of origin of the infertile men. Comparatively to men from non-MENA regions, infertile men from the MENA region had significantly lower semen quality (Elbardisi *et al.*, 2018).

As the Arab majorities are Sunni-Muslims, IVF clinics appeared first in Arab countries and in Saudi Arabia in 1986 i.e. few years after its discovery which was in 1978. That delay was due to Islamic concerns about these techniques until it was announced Halal by scientific and religious bodies, included Dar El Iftaa, Cairo (1980) and the Islamic Fiqh Council, Makkah (1984), the Islamic Organization for Medical Sciences in Kuwait (1983), International Islamic Fiqh Academy in 1986, and the International Islamic Centre for Population Studies and Research, al. Azhar University (Al-Bar and Chamsi-Pasha, 2015).

In general, Arab countries follow Sunni authorities view except Lebanon which accepted a mixture of Sunni and Shia views (Inhorn *et al.*, 2017). Marriage and family formation are extremely encouraged in Qur'an and Hadiths as the sole way of procreation in Islam (Al-Bar and Chamsi-Pasha, 2015). Based on that, most ART interventions are permissible in Arab countries provided that the treatment includes only the gametes of a wife and a husband during the period of their legal marriage and in the uterus of that wife (Al-Bar and Chamsi-Pasha, 2015; Inhorn *et al.*, 2017). All forms of

third-party ART as donation and surrogacy are prohibited by Arab countries' law (Inhorn *et al.*, 2017). An exception is Lebanon in which gamete donation is allowed (Inhorn *et al.*, 2017). The majority of infertile Sunni couples who need gamete donation are aware and agreed upon the Islamic prohibition of third-party ART and totally believe against this kind of intervention to avoid adultery and preserve kinship (*nasab*) (Inhorn *et al.*, 2017).

A systematic review about ART in the low and middle income countriesreported eight citations from Arab world, most of them from Iran and Egypt (Chiware *et al.*, 2020). However, lack of registration in most Arab countries make it difficult to estimate ART-related numbers there. As per the available registries, pregnancy rate after IVF/ intracytoplasmic sperm injection (ICSI) ranged from 22%-35% (Mansour *etal.*, 2014; Almaslami *et al.*, 2018). Male factor was the most common single indicationof IVF (Almaslami *et al.*, 2018).

A study about ART was conducted in a single-centre study in Al-Qassim district in Saudi Arabia which collected data from medical records between 2014 and 2016 (Almaslami *et al.*, 2018). The results showed that the outcomes were within the average international success rate, and rate of utilization of IVF/ICSI cycles was about 1000 cycle per million inhabitants. The mean age was 33$\pm$6 and 39$\pm$7 years for women and men respectively. About 55% had secondary infertility and male factor was the predominant indication of IVF/ICSI. The overall clinical pregnancy rate per embryo transfer was 35%. However, the age specific pregnancy rate was the highest (40%) for women below the age of 35, and the lowest (12%) for those who are above 40 years.

1.4 Overview of infertility management

Infertility is a preventable disease in a substantial subset of patients. Prevention includes both primary prevention as in case of preventing sexually transmitted diseases and thereby tubal factor infertility, and secondary prevention by treating modifiable factors in infertile couples like smoking, obesity, and environmental exposures (Withers, 2021). Tertiary prevention is needed to prevent the sequalae of infertility especially the psychological and social consequences (Shreffler *et al.*, 2020).

Infertility work-up should be offered to couples who meet the diagnosis of infertility or are at risk (ACOG, 2019). Earlier evaluation and treatment is indicated for women aged 35 year and older after six months of failed attempted pregnancy, and even sooner for those who reached 40 because female fertility declines toward the age of 40 (ACOG, 2019).

There are many infertility treatments options. The approach to infertile couple requires holistic overview and careful assessment to pick up the best treatment. In many cases, medically assisted reproduction is needed. Medically assisted reproduction is a broad term, as defined by The International Glossary on Infertility and Fertility Care, includes the various interventions and procedures to treat fertility impairment and achieve reproduction such as ovulation induction (OI) or stimulation, insemination, ART, and uterine transplantation (Zegers-Hochschild *et al.*, 2017).

The evolution of ART by Robert Edwards with its success in achieving the first live born in 1978 by in-vitro fertilization made a historical event in infertility treatment (Edwards and Steptoe, 1978). ART includes all interventions aiming to achieve reproduction by the in vitro handling of both human oocytes and sperm or of embryos, examples are IVF and embryo transfer, ICSI, preimplantation genetic testing, assisted hatching, gamete intrafallopian transfer, zygote intrafallopian transfer, cryopreservation

of gamete and embryo, and donation (Zegers-Hochschild *et al.*, 2017). A brief illustrative description of some common techniques is shown in Figure 1.1. ART contributed to 1 – 4% of all infants born in the United States (US) (Sunderam *et al.*, 2019).

At least basic evaluation of both heterosexual partner is indicated concurrently once the diagnosis of infertility is met due the increasing prevalence of male factor infertility (ACOG, 2019). Concerning infertility treatment approach, the first step is to provide accessible information for infertile couple, and address the psychosocial effect of infertility and evaluate couple's quality of life (NICE, 2017). Initial work-up for infertile couple includes the following; history for both partners; semen analysis for male partner, and the following for the female partner; physical examination, tests for ovarian reserve, ovulatory dysfunction, tubal and uterine factors (Penzias *et al.*, 2021).

Treatment of female infertility was summarised by Walker and Tobler (2022) includes identifying the cause of infertility as the treatment aims to correct the causes if possible or overcoming them if uncorrectable. This includes lifestyle modification to improve fertility. Generally speaking, treatment modalities of female infertility includes OI as in some cases of ovulatory dysfunction, surgical management like in hydrosalpinx, and ART as in severe tubal disease (Walker and Tobler, 2022). However, in male factor infertility ART is the treatment of choice for most cases because only minority of them have reversible causes that can be handled medically or surgically (Carson and Kallen, 2021).

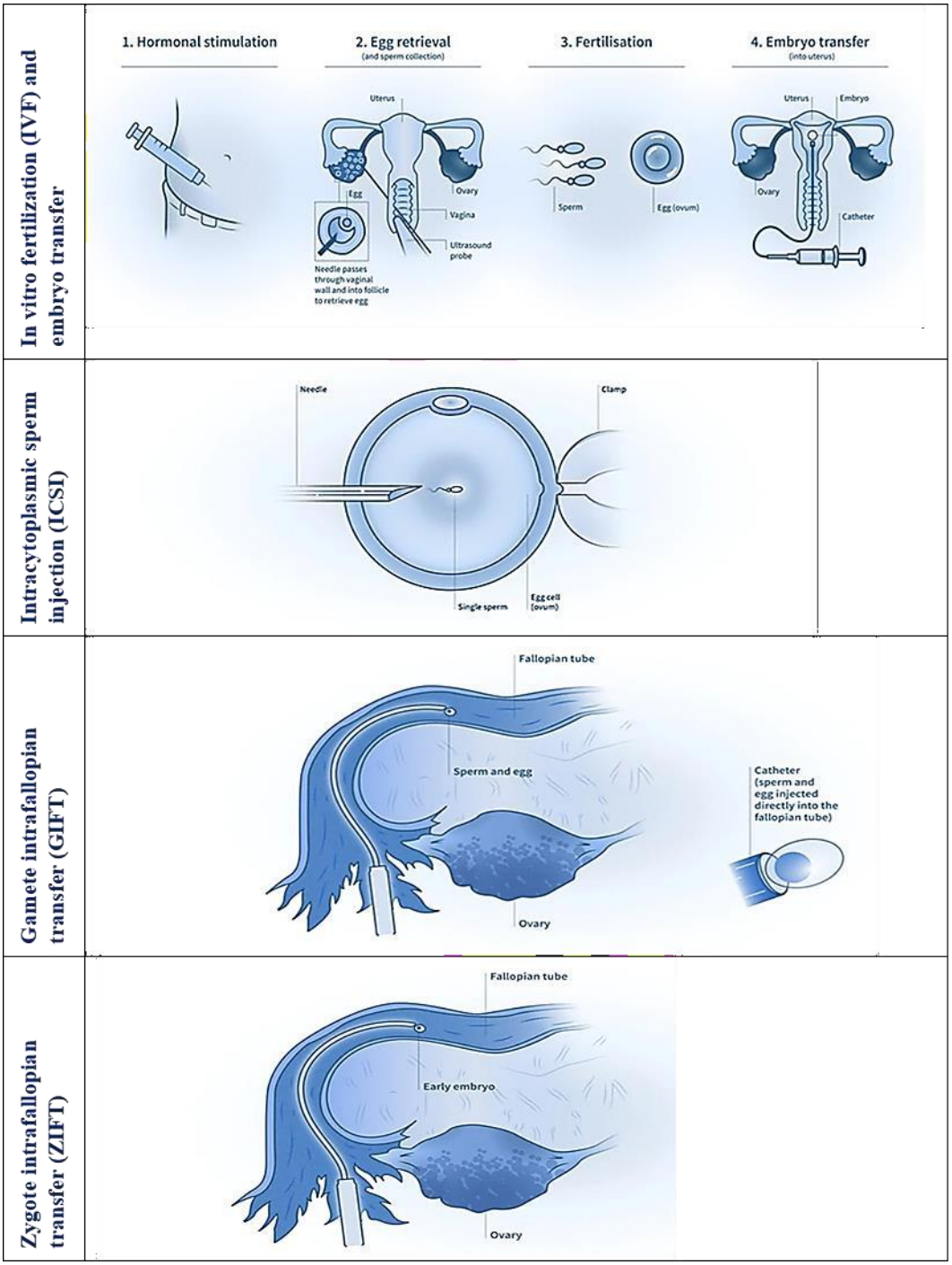

Figure 1.1 Assisted reproductive technology interventions
All figures are adapted from: (Fertility.com, 2023)

Family physicians have an important role in infertility care as they are the initiatives of infertility work-up for both parents to guide timely referral to specialist

clinic as indicated (Thable *et al.*, 2020). In addition, family physician should provide formal counselling addressing the psychological effects of infertility, and ongoing and supportive care which are important steps for infertile couples because of the associated anxiety and psychosocial stress with infertility experience (Lindsay and Vitrikas, 2015; NICE, 2017). Arab family physicians showed positive attitude, perception, and practice in infertility management (Al Obaid *et al.*).

1.5 Women infertility care journey and infertile women's help-seeking behaviour (HSB)

Childlessness is associated with painful psychosocial consequences because the desire to have children is closely linked to the benefits of being a parent, and getting societal recognition and family support (Kyei *et al.*, 2021). Indeed, infertility differs from other diseases in that it is related to two body systems each one is in different human body. So, it affects two persons at the same time; the infertile couple.

However, there is extreme difference in the aetiology, management, and before this and that the role of men and women in the reproduction process. Expectedly, women perspective and experience in fertility care found to be different from their partners (Nagórska *et al.*, 2019; Gullo *et al.*, 2021).

Therefore, exploring infertile persons as a couple may not allow comprehensive coverage of each of them because of the gross differences explained. It is well-known that infertility is disabling even in men, but concerning exploring infertility care it is worth to start by the heaviest contributors. The infertility itself put a higher burden on women as compared to men especially in the low and middle income countries (Wang *et al.*, 2022). In many cultures, not invariably Arab, woman is the first responsible of

reproduction and therefore frequently blamed for infertility; womanhood is defined through motherhood (Hamdan, 2016; Ibrahim *et al.*, 2019; Reaves and Hauck, 2019).

In addition, especially after the development of ART, women carry the major part of infertility treatment even if the cause was male factors or unexplained (Turner *et al.*, 2020). This means that women have to go through the nasty journey of infertility care despite knowing that she is not the cause of the problem. Although male factor infertility is increasing progressively, Arab men still hardly accept being infertile and feel this injures their manhood (Dupont, 2016). As a result, the process of infertility care usually starts by women.

Infertility among Arab infertile women was associated with negative psychological experiences such as self-rejection, depression, stress, solitude, and social and marital instability (Hamdan, 2016; Mahadeen *et al.*, 2018; Wang *et al.*, 2022). Furthermore, having children is one of the indicators of successful marriage, if not achieved could threaten family continuity, lead to marital instability, intimate partner violence and even to divorce (Hamdan, 2016; Mahadeen *et al.*, 2018; Wang *et al.*, 2022).

In many cultures, including Arab and Muslims, children are the future support of their parents physically and economically therefore childless women feel unsecure and worry about their future (Hamdan, 2016; Reaves and Hauck, 2019). All these factors contribute to stigmatizing the infertile women and the negative psychosocial sequelae (Hamdan, 2016; Jrade, 2016).

The journey of receiving infertility care is often lengthy and stressful on the psychosocial and emotional levels (Annual Capri Workshop Group, 2019; Morrison, 2022). Therefore women, especially those with long period of infertility, use several coping strategies during ART seeking journey such as avoiding challenging

circumstances and accepting the fact that difficulties will always exist (Casu *et al.*, 2019; Kyei *et al.*, 2022).

'Help-seeking' and 'health-seeking' behaviour are often used interchangeably in the literature. However, some researchers considered 'health-seeking behaviour' part of the main concept 'help-seeking behaviour' which focuses on medical care seeking (Pushpalata and Chandrika, 2017). For the purpose of our study, both terms were used interchangeably. The prevalence of infertile patients seeking any kind of medical care ranged from 42 to 76%, with only 22% actually receiving medical treatment, according to a review study of medical help-seeking for infertility in developed countries (Passet-Wittig and Greil, 2021b). However, there were many steps involved in seeking ART, such as consulting a doctor, having tests done, and beginning treatment. The highest step reached could be far beyond starting medical treatment and becoming pregnant (Passet-Wittig and Greil, 2021b). Despite the strong desire of achieving take home baby by many infertile couples, people frequently did not seek/continue medical care for infertility which reached as high as 50% (Passet-Wittig and Greil, 2021b; Ghorbani *et al.*, 2022).

Infertile couples frequently suffer from difficult access to infertility care especially ART because access is varied greatly among countries and regions being the lowest in lower- and middle-income countries (Adamson *et al.*, 2018). One of the important obstacles against access is the financial issues related to ART treatment (Li *et al.*, 2018). Asia and Oceania Federation of Obstetrics and Gynaecology survey in 2015 revealed that the typical cost of IVF per treatment cycle was at least USD 2500 in all the 23 responding countries (Li *et al.*, 2018). This cost exerts a significant economic burden to infertile couples and might not be affordable.

Insurance coverage for infertility care especially ART cost is extremely variable among countries and it is a problem not only in low and middle income countries, but in some high income ones as well (Kelley *et al.*, 2019; Ombelet, 2020). Based on The International Federation of Fertility Societies surveillance report, ART cost coverage in the participating Arab countries is as follow; Egypt, Lebanon, Jordan, and Sudan provided no coverage. Tunisia and Morocco reported partial coverage or reimbursement. Qatar and the United Arab Emirates reported complete coverage or reimbursement (Allan *et al.*, 2022).

In Saudi Arabia, no available government subsidy for ART (Li *et al.*, 2018) and it is not covered by insurance in the private sector (CCHI, 2019). ART accessibility is still an ongoing problem in many areas worldwide. Literature highlighted the financial barrier of infertility care and recommended to reduce the cost of ART and to cover the infertility care cost by the health insurance considering fertility care a human right (Gipson *et al.*, 2020; Kawwass *et al.*, 2021). Moreover, access to infertility is further affected by pandemics like what happened during the coronavirus disease crisis in 2019 (COVID-19) which significantly affected infertile couples physically and psychosocially (Rallo *et al.*, 2021; Seifer *et al.*, 2021).

Barriers to infertility care pushed the patients to cross the borders and take all the subsequent loads and suffers aiming to achieve their dream of take-home baby (Salama *et al.*, 2018; Simopoulou *et al.*, 2019). Nevertheless, in addition to the barrier discussed above against fertility care; the psychological and demographic factors were the most common reasons for dropout infertility care which was confirmed by studying insured patient (Domar *et al.*, 2018; Ghorbani *et al.*, 2022; Kuhnt and Passet-Wittig, 2022). Unfortunately, even for those who overcame the barriers and had received ART, the success rate remains a major concern as the global pregnancy rate for nondonor

IVF/ICSI ranged from 20-28%, and the global delivery rate is 17-22% after all that cost and suffer (Adamson *et al.*, 2018).

After understanding the nature of the problem and infertility care journey, it is not a surprise that stress affected around 80% of infertile women and it is certainly associated with infertility diagnosis and treatment (Patel *et al.*, 2016). Infertility treatment especially ART increased the risk for depression and anxiety disorders among women (Nicoloro-SantaBarbara *et al.*, 2018; Carvalho *et al.*, 2021). However, infertile couples are nine times more likely to experience depression than fertile ones (Fallahzadeh *et al.*, 2019). Furthermore, women who are infertile have a three times greater chance of developing anxiety than women who are fertile (Fallahzadeh *et al.*, 2019). In addition, infertility treatment stress influenced pregnancy rate and clients drop-out (Rooney and Domar, 2018).

Therefore, spiritual as well as psychological assessment and support during all stages of fertility care has been recommended as many infertile couples have negative attitudes toward psychological services and seldomly seek that support (Romeiro *et al.*, 2017; Zurlo *et al.*, 2020).

1.6 Quality health care requires a holistic, patient-centred approach

The past concept of fertility care quality that focused on outcome measures has been changed. Patient-centredness or patient-centred care (PCC) is now increasingly recognized as an important determinant of fertility care quality (Borghi *et al.*, 2021). Enid Balint is the first who described the term "Patient-centred medicine" in 1969. He stated that the patient should be viewed as a unique human being and the illness should be viewed as an incident or aspect of the unique person (Balint, 1969).

After its origin, PCC has been studied for several decades. Numerous definitions have been evolved but unfortunately, we still lack a universal definition of PCC (Byrne *et al.*, 2020). Research has shown that the most accurate way to define PCC is through the patient's perspective (Picker Institute, 2023).

The Picker Institute's eight principles form the foundation of the majority of PCC concepts. Seven dimensions of PCC were developed as a result of research carried out by Harvard School of Medicine in 1986 for the Picker Institute and the Commonwealth Fund. The study used a variety of focus groups in addition to a literature review (Picker Institute, 2023). The dimensions' development was traced and documented in 1993 in the book "through the Patient's Eyes: Understanding and Promoting Patient-Centred Care" (Groene, 2017). These dimensions are: respect for patients' values, preferences and expressed needs; coordination and integration of care; information, communication and education; physical comfort; emotional support and alleviation of fear and anxiety; involvement of family and friends; and transition and continuity. In 1987, the dimensions were renamed as "the Picker principles of PCC' and the eighth principle 'access to care' has been added (Picker Institute, 2023).

Patient-centredness has been first announced as one of six main goals of healthcare in 2001 by the Institute of Medicine (IOM, 2001). It was defined as 'care that is respectful of and responsive to individual patient preferences, needs and values,and ensuring that patient's values guide all clinical decisions'.

Despite the widespread emphasis on PCC in healthcare, its application is still challenging and many professions are still struggling to practice PCC and to make decisions based on patients' preferences (Agha *et al.*, 2018; Bokhour *et al.*, 2018). There are countless number of studies about the PCC in specific health care settings e.g. primary care, dementia patients, patients with chronic diseases, pregnant women, and

paediatric patients (Park *et al.*, 2018). Literature showed that infertile couples need a couple-centred approach, with more psychosocial support (Borghi *et al.*, 2021).

Dancet et al. (2010) conducted a systematic review to identify patient perspectives in fertility care in developed countries. Fifty-one studies were selected most of which assessed patients' perspectives, expectations or satisfaction in relation to one aspect of fertility care e.g. consultation, fertility investigations, information provided, transition of care and pain medications. More than half of the studies were conducted in Europe, one fifth in the US, and only one was in the Middle East (Israel) aimed to evaluate patient's satisfaction with pain medications during oocyte retrieval in l999. The review revealed significant methodological limitations in the included studies. It found that infertile patients valued nine dimensions of PCC namely ‘fertility clinic staff’, ‘skills’ in addition to seven dimensions are from the Picker’s patient-centeredness principles (Dancet *et al.*, 2010).

Patient perspectives actually differ according to their culture and health care system so the first step of planning and implementing PCC is to listen to the patients and define what they prefer and value (Bokhour *et al.*, 2018; Ekman *et al.*, 2021). In 2011, Dancet et al. defined what patients mean by PCIC through a qualitative study. They reported 10 detailed dimensions divided into system and human factors with a two-way interaction between them (PCIC model from the patient’s perspective). In the same vein, Van Empel et al. (2010) explored infertile couples experience focusing on needs, strengths and weaknesses of fertility care . Emotional support and continuity of care were the areas of weakness.

Infertile patients and fertility care providers have different preferences for fertility treatment; providers overestimate ‘success rates’ (Cai *et al.*, 2014) and

'continuity of care' (Aarts *et al.*, 2011). Women place a significantly higher value on various aspects of fertility care than do their partners (Holter *et al.*, 2014a).

However, defining the concept of PCIC through the patient's voice is important but its application should be measured as well; it gives feedback to healthcare system to address quality issues and improve health outcomes (WHO et al., 2018). There should be quality indicators at various levels of health care system preferably using information from patient experience as a useful tool for health care quality measurement including PCC (Santana *et al.*, 2019; IAPO, 2023).

Few validated instruments for measuring PCC in fertility care have been developed. Van Empel et al. (2010) developed a 124-item questionnaire to investigate infertile couples' experiences in 13 Dutch fertility clinics. After that, the Patient-Centred Questionnaire- Infertility (PCQ-infertility) was developed and extensively validated for use in Netherlands and across Europe (van Empel *et al.*, 2010; Dancet *et al.*, 2012). In 2012, quality of care from patient's perspective for IVF treatment (QPP-IVF) tool has been developed and validated in Sweden (Holter *et al.*, 2014b). Recently, the tell me tool was developed to assess couples' experience of infertility treatment, including shared decision making following the principles of user-centred design (Verkerk *et al.*, 2022). However, all these tools were developed and/or validated among patients from Europe or other Western countries.

Patient-centredness has been studied in relation with many outcomes including quality improvement (Hong and Oh, 2020), patients' trust in healthcare providers (Hong and Oh, 2020), quality of life (Liu and Yeo, 2023), and patient satisfaction (Kuipers *et al.*, 2019). Thus, it has been recommended that we focus our efforts on psychologically supporting infertile patients by determining the most effective way to provide physical, emotional, and psychological care through the practice of PCIC (Domar, 2020).

1.7 Are the available PCIC concept, its measuring tool, and HSB findings applicable in Arab countries?

The available concept which comprehensively defined PCC among infertile patient is the European concept by Dancet et al. (2011). As explained earlier, it was defined based on the result of focus group discussions with Dutch speaking 46 heterosexual couples, nine individual heterosexual women, and one lesbian couple. All patients were from Belgium and the Netherlands.

In the same line, the reliable and valid tool which measure PCIC in general is the PCQ-infertility which was developed on the light of seven focus group discussions and validated on 888 Dutch infertile couples, both heterosexual and lesbian, in the Netherland. Populations are of different culture, context, and religion if compared with our study population; being non-Muslim and non-Arab people. Similarly, studies which described infertile patients HSB in details were in developed Western or non-Arab countries as clarified in the literature review chapter.

A qualitative study explained the impact of culture on patients perspectives by conducting 26 focus group discussions including patients from three different ethnic/racial groups to define the concept of respect in healthcare (Beach *et al.*, 2017). They found that patients' perception of respect differed to some extent among African American, Latino, and white patients. Furthermore, they noticed that participants added several points to the concept of respect that are not commonly included in the literature. They concluded that understanding different patients' perspectives is vital to define and apply PCC (Beach *et al.*, 2017) because the respect is one of the dimensions of PCC proposed by the Picker institute (Picker Institute, 2023). In the same vein, Devlin et al (2016) came up with different preferences regarding the design features of hospital rooms as evaluated by 78 patients in the United States and 158 in Portugal.

The difference is even more prominent if we compare Arab and Western cultures. An example is the difference of core identity values across cultures which affects how the patients could perceive the professionalism, define the good physician, and seek medical care. In Arab countries, examples of these core values are the faith in God (Allah) and accountability to Allah which makes people expecting rewards from Allah and therefore being motivated to do perfect and helpful things to others regardless of the amount of the rewards they are receiving from people (Helmich *et al.*, 2017). Accountability in Western tradition is known as divine accountability and is recognized as core value in the Western tradition but is not strongly expressed like in Arab culture (Helmich *et al.*, 2017).

Actually, religion and culture are inseparable and it is very clear that each one is affecting the other in a complex way (Jha and Robinson, 2016). The above example clearly showed that integration and how the Islam shaped some of the Arab culture core values. Thus, we expect substantial variations in norms and values in Arab Muslims if compared with European Muslims. In the same vein, Jha and Robinson (2016) gave an example of how the Catholicism practices differed by culture being more conservative in Middle East if compared with the Western Europe.

The influence of Islam on patient perspectives on infertility care and HSB is of utmost significance. Religion affects the way patients cope with infertility and their choices and preferences for infertility medical care (Inhorn *et al.*, 2017; Kyei *et al.*, 2022). This chapter discussed the Islamic prohibition of third-party ART (Al-Bar and Chamsi-Pasha, 2015) including homosexual reproduction which is based on donation with or without surrogacy. However, the majority of infertile Sunni Muslim couples are totally aware about the reason behind this prohibition and strongly believe against using third-party ART to preserve kinship (*nasab*) (Inhorn *et al.*, 2017). Conversely, various

third-party reproduction techniques are allowed in most European countries (Allan *et al.*, 2022), as evident in Dancet et al.'s (2011) sample, which included one lesbian couple to define patient-centred infertility care (PCIC). Notably, religion was not mentioned within the dimensions of PCIC or PCQ-infertility.

In addition to culture and religion, context can affect patient healthcare preferences and priorities. For example, cost was mentioned as the primary barrier to infertility care by American women regardless of race or ethnicity. However, the European patients who defined PCIC did not place as much emphasis on this factor (Dancet *et al.*, 2011; Dancet *et al.*, 2012; Insogna *et al.*, 2020). In most Arab countries, the government or insurance systems do not cover ART costs, which is a substantial contextual difference (Allan *et al.*, 2022).

1.8 Problem statement

Infertility is a global health concern; it is prevalent in Arab countries as well (CDC, 2022). Globally, one in six couples suffering from infertility in their lifetime (WHO, 2023). Despite advances in infertility care, particularly ART, numerous couples still struggle to achieve their aspirations. Unfortunately, infertility care frequently necessitates a long and complicated journey, profoundly affecting couples grappling with infertility, with no guarantee of success (Casu *et al.*, 2019). Even women who eventually attain pregnancy are vulnerable to challenges (Dayan *et al.*, 2019). Women typically play the most challenging roles. Therefore, infertile women are more prone to anxiety, depression, marital instability and partner violence (Wang *et al.*, 2022). Infertility-specific stress prevalence reached 80% among women, regardless of the type of infertility treatment (Pozza *et al.*, 2019). Nevertheless, women who receive the invasive treatment modalities of IVF/ICSI are more susceptible to physical, financial,