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Exploring patient-centered infertility care among Arab infertile women: a qualitative study

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TITLE Exploring patient-centered infertility care among Arab infertile women: a qualitative study

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ABSTRACT

Objective: The current study aims to define patient-centred infertility care (PCIC) from the perspective of Arab women with infertility.

Method: Semi-structured in-depth telephonic interviews were conducted with Arab women with infertility from January 2017 to December 2018 to explore the concept of PCIC from their perspective. A purposive sample of 14 women was included with maximum variation. The sample included Arab women who received infertility treatment during the six months preceding the interview at any hospital in Jeddah, Saudi Arabia. We recruited participants until data saturation was reached and no new themes emerged. An interview guide covering the scope of patient experiences and how patients defined PCIC was used. Interviews were audio-recorded and transcribed verbatim. Data were analysed using an inductive thematic analysis.

Results: Participants highlighted nine important PCIC dimensions. Of these, four were agreed upon by all participants: accessibility, minimising cost, information and education, and staff attitudes and communication. The remaining five dimensions were staff competence, physical comfort, privacy, psychological and emotional support, and continuity and coordination of care. The concept of PCIC was related to three major contributors: participants' demographics, patient experience with infertility care, and health seeking behaviour (HSB). Applying PCIC dimensions on Maslow's hierarchy revealed that participants were still in the deficiency zone, which could possibly explain the differences between Arab and European models.

Conclusion: We found clear differences between the Arab and the European PCIC model. Arab infertile women are still having many basic unmet needs. The current study provided PCIC dimensions and items, which can be used to improve the quality of Arab infertility care.

Keywords: Patient-centred care, infertility, women's health services, Arab world

ARTICLE SUMMARY

Strengths and limitations of this study

- This study may become a reference for the concept of patient-centered infertility care in the Arab world and helps to improve the quality of infertility care.
- The current study showed the possible association of PCIC and HSB which has not been studied in the literature.
- Our study was limited by being conducted in a single city. Collecting data from across the Arab world would be more representative.

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INTRODUCTION

Infertility is a worldwide public health concern.[1] Globally, the estimated infertility rate is between 3·5% to 26·4%; however, the burden is higher in developing countries, where approximately one in four couples is affected.[2-4]

The infertility care journey is invariably long and full of emotional and psychosocial stress.[5 6] Couples experiencing infertility frequently face difficult access to infertility care—especially assisted reproductive technologies—as access varies widely among countries and regions, and is lowest in lower and middle income countries.[7]

Previously, conceptualisations of infertility care quality focused on outcome measures.[8 9] However, this is changing, as patient-centred care (PCC) is increasingly recognised as important for infertility care quality.[10-12] Patient-centred infertility care (PCIC) was studied among European couples experiencing infertility,[13 14] and the following ten dimensions were identified: information provision, competence of clinic and staff, continuity and transition, coordination and integration, accessibility, physical comfort, attitude of and relationship with staff, communication, patient involvement and privacy, and emotional support.[10 13] These served as the basis for the Patient-Centredness Questionnaire-Infertility, validated for use among European populations.[12]

A literature review conducted in 2017 failed to define PCIC from the perspective of Arab patients experiencing infertility; thus, the question remained unanswered.[15] What was validated in Europe might not be in the Arab world, due to regional and cultural differences believed to affect infertility care, including counselling and treatment modalities.[16] Thus, we aimed to explore the concept of PCIC among Arab women experiencing infertility in Saudi Arabia.

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METHODS

Design

This is a qualitative study using in-depth interviews (IDIs) to explore the concept of PCIC from the perspective of women experiencing infertility**.**

Study population

Between January 2017 and December 2018, we conducted IDIs in Jeddah, Saudi Arabia. Inclusion criteria were Arab women who received medical treatment for infertility during the six months preceding the interview, at any hospital in Jeddah. A purposive sample of 14 women was included, with maximum variation. The aim behind maximum variation sampling was to gain greater insight into PCIC by viewing it from different angles. Variations included age group, level of education, occupation, duration of marriage and infertility, infertility type, number of living children, treatment used, health facility visited, and duration of seeking infertility care. Participants were recruited purposefully until data saturation was reached and no new themes emerged.

Data collection and analysis

We conducted IDIs via telephone. IDIs length ranged from 45 to 90 minutes. All IDIs were conducted by a female researcher, family physician with experience in qualitative data collection (HHW). We used IDI guide to collect data flexibly. The researcher started by introducing herself as a researcher and family physician interested in patient-centered care. Then the consent was obtained including clear explanation of the aim of study for each participant. The IDI guide consisted of 2 parts; part one included participants' characteristics, part two included a question regarding medical care received, followed by six open-ended questions regarding PCIC (Supplementary file 1). We used probing questions as needed. Each interview was audio recorded, transcribed verbatim, translated from Arabic to English, then imported to NVivo version 12 for analysis.

We used inductive coding thematic analysis, as patient centeredness had not been defined from Arab patients' perspectives. We described, compared, and related findings throughout data analysis. The first step in the analysis was reading and re-reading the transcripts several times, to become familiar with emerging data. At this stage, we made hand notes summarising the main points and our early impressions. These notes focused on mapping patients' experiences with infertility care and their

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definitions of PCIC (Supplementary file 2). Next, we (HHW & TATI) used line-by-line coding independently for each IDI. We continuously developed and modified the codes during IDI analysis. When we completed coding for five IDIs, we discussed and modified the codes before moving forward. Discrepancies were discussed until consensus was reached. If no consensus was reached, we discussed that point with the third author (SBI). Then, we categorised codes into preliminary subthemes and themes.

We reached saturation after 14 IDIs, and derived around 148 codes. We continuously reviewed and modified our preliminary themes until we developed the final themes. Matrix queries produced by NVivo were used to display the frequency of codes occurring within the text, or of codes and participants' characteristics. This matrix allowed us to assess the degree of agreement among participants and the nature of the associations.

We adopted four methods to enhance validity. First, we assessed different aspects of the same concept. The IDI guide included six questions about PCIC; however, they were worded differently by asking about participants' positive and negative perceptions of care experience, what they needed from infertility care, what would be an optimal situation, and, finally, a direct question about participants' definitions of PCIC. Second, source triangulation was used by ensuring maximum variations in the sample to explore PCIC from different viewpoints. Additionally, two gynaecologists were asked about concerns in infertility care addressed by participants, such as wait times and financial aspects. In addition, after completing data analysis, we compared PCIC dimensions from the current study with those identified by European participants, the only available PCIC dimensions from patients' perspectives before our research. Third, we used analyst triangulation, with three analysts involved in reviewing the findings. Fourth, we used respondents' validation. After data analysis, we sent participants a summary of the PCIC dimensions and their items. All agreed the dimensions they preferred were included. Two respondents stressed on avoiding long wait times and providing appropriate appointments for the purpose of follow-up visits. The results are reported according to Consolidated Criteria for Reporting Qualitative Research (COREQ)[17] (Supplementary file 3).

Patient and public involvement Patients and/or the public were involved in the conduct, and reporting of this research. Refer to the Methods section for further details.

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RESULTS

Table 1 shows participants' characteristics. Thematic analysis provided three themes: (1) PCIC dimensions, (2) PCIC definition and patient experience, and (3) PCIC and health seeking behaviour (HSB). The third theme included subthemes. As shown in Figure 1, there was interaction between participants' definitions of PCIC and patient experience, HSB, and their sociodemographic characteristics.

Table 1: Characteristics of participants involved in in-depth interviews (n=14)

Participant characteristics		**Number(%)**
Age, year	25-	5 (35·71%)
	30-	3 (21·43%)
	35-	3 (21·43%)
	40-45	3 (21·43%)
Residency	Jeddah	10 (71·43%)
	Out of Jeddah	4 (28·57%)
Duration of marriage, year	1-	7 (50·00%)
	5-	3 (21·43%)
	10-	1(7·14%)
	15-20	3 (21·43%)
Duration of infertility, year	1-	7 (50·00%)
	3-	5 (35·71%)
	6-	1 (7·14%)
	9-	1 (7·14%)
Duration of seeking infertility care, year	1-	8 (57·14%)
	3-	4 (28·57%)
	6-	2 (14·29%)
Number of living	0	8 (57·14%)
	1or 2	5 (35·71%)
	3 or more	1 (7·14%)
Type of infertility	Primary	5 (35·71%)
	Secondary	9 (64·29%)
Pregnant now	Yes	2 (14·29%)
	No	12 (85·71%)
Type of treatment used	Medical (OI*, hyperprolactinemia)	13 (92·86%)
	IUI†	1 (7·14%)
	ICSI/IVF‡	3 (21·43%)
	Surgical	6 (42·86%)

*OI; ovulation induction, †IUI; intrauterine insemination, ‡ICSI/IVF; Intracytoplasmic sperm injection/in-vitro fertilization.

PCIC dimensions

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We identified nine PCIC dimensions from 14 IDIs. Table 2 summarises the dimensions and each of their items, ordered following a logical stream, similar to what patients experience during infertility care.

Table 2: Patient-centred infertility care (PCIC) dimensions from Arab infertile women perspective

PCIC dimensions	PCIC items
Accessibility	Availability of appropriate appointments
	Ease of access to the health care facility
	Smoothness of the process of booking appointment, registration & workflow
	Justice in handling appointments & patient access
	Providing easy access to doctors through phone & online consultations
	Short wait time
	Vacancy (no overcrowding)
Minimising cost	Covering infertility care cost by insurance
	Provision of infertility management in public sector free of charge
	Providing infertility care at reasonable, affordable cost
Physical comfort	Cleanliness
	Comfortable environment
	Assistance and provision of care
	Pain avoidance and relieve
	Single dose, less frequent medication doses
Privacy	Providing care in special department for women & infertility
	Providing female doctors or examiners
	Avoiding over or unnecessarily exposing intimate parts of patient's body
	Considering differences in privacy mean from patient to another
	Ensuring minimal interruption and number of people in, no men or other patients
	Taking patient permission before allowing more people in
	Preferring nobody knows about patient's infertility issues
	Considering differences in the preferences regarding husband involvement
Staff attitude and communication	Treating patient and other staff with dignity and respect
	Staff truthfulness
	Avoiding materialistic behaviour
	Practicing medicine in love and dedication
	Being so patient
	Religious approach
Staff competence	well-known doctors
	Proper and accurate evaluation; history, examination and investigations as needed
	Understanding the patient fast and well
	Providing diagnosis and curative solutions
	Avoiding medications with bad side effects
	Providing comprehensive and personalized care
	Qualification

(Table 2 continues on next page)

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PCIC dimensions	PCIC items
Information and education	Giving and taking, encouraging discussion and negotiation.
	Providing relevant information about the patient status, progress, and prognosis.
	Disclosure and clarification of all treatment options.
	Providing information on processes of care before each step, what to expect before, during and after procedures, then home care, plan of care, and follow up.
	Informing patient about the use, expected effects, and possible side effects before starting treatment
	Providing relevant information with adequate explanation
	Talking to patients with simple understandable language
	Welcoming patient questions and providing answers thought health care journey.
	Raising health awareness and education through school education, doctors in clinics, and campaigns
	Considering the patient's long experience as an expert in her case
Psychological and emotional support	Listening to patients
	Considering the patient's personal situation
	Preparing patient psychologically throughout her treatment journey
	Giving patient realistic hope
	Avoiding using destroying words or attitude, or pointing finger at the patient
	Ensuring ongoing support and motivation
Continuity and coordination of care	Studying the patient case well including proper documentation and up to date file review
	Treating couple as one case
	Developing and sharing detailed plan of care from the start
	Ongoing planning, follow up and coordination of care hand on hand with the patient based on health situations and patient needs
	Providing follow up with the same doctor
	Including doctors from same specialty and other specialties as needed
	Facilitating the shortest treatment journey
	Encouraging lady's check-up before marriage

All participants mentioned four dimensions as important elements of PCIC: accessibility (short wait times), minimising cost (providing infertility care at a reasonable, affordable cost), information and education (providing relevant information with adequate explanation), and staff attitudes and communication (treating patients and other staff with dignity and respect). Information from obstetricians/gynaecologists supported participants' perspectives regarding wait times and costs. Despite being noted as important dimensions, participants' preferences varied regarding maximum wait times, relevant information, and privacy during infertility care. These preferences were affected to some extent by participants' educational level, infertility care experience, and marital relationship quality. Table 3 compares these dimensions with the European PCIC model.

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Table 3: Comparison between the Arab and European Patient-centered infertility care (PCIC) dimensions

Arab PCIC dimensions	European PCIC dimensions
1. Accessibility	1. Accessibility
2. Minimizing cost*	..
3. Physical comfort	2. Physical comfort
4. Privacy	3. Patient involvement* and privacy
5. Staff attitude and communication	4. Attitude of and relationship with staff 5. Communication
6. Staff competence	6. Competence of clinic and staff
7. Information and education	7. Information provision
8. Psychological and emotional support	8. Emotional support
9. Continuity and coordination of care	9. Coordination and integration, 10. continuity and transition

*Indicates the dimension mentioned in one model only

PCIC definition and patient experience

When asked to define PCIC, participants provided short definitions focused on a few points, although they mentioned much more during the preceding questions about their infertility care experience. The panel (Supplementary file 4) shows participants' definitions of PCIC and summarises each participant's experience.

Most participants had a dominant issue during infertility care. These issues were related to the medical care itself or sociodemographic circumstances. Participant experience was found to shape participants' definitions of PCIC the most, as shown in the panel.

PCIC and HSB

PCIC dimensions showed influences on participants' HSB, suggested by the following HSB subthemes.

1. Self-medication

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Participants practiced two methods of self-medication: using medications illegally, and using traditional or herbal medicines.

The first method is not a responsible form of self-medication, based on WHO's definition [18]. One patient used ovulation induction medications (Clomiphine citrate tablets, Menotropin injections, Choriomon injections) in high doses, reaching double the dosage prescribed by her physicians. All were prescription-only medications.

'I used to order images for myself for ovulation. I knew the size of the egg, they (doctors) got annoyed! Yes, I got the image and ask for a trigger shot, because sometimes we had a relation before meeting the doctor. I wanted to know, but sometimes you do not find the answer you are looking for….Now I knew, if the egg was more than 15, I should take the trigger shot', Participant 10, secondary infertility

She did not ask her doctors to increase the dose, because she felt they were 'fed up' with her many questions and requests. Additionally, appointments were far; therefore, if she waited to meet her physician each time to get the prescription, she would have very long treatment journey.

For the second method, most participants (12 out of 14) used traditional and/or herbal medicine during infertility care. Remedies included herbs, honey, cupping therapy (Hijamah), massage, and Qur'anic verses read to achieve some betterment (Roqia). Participants had different attitudes towards this kind of medicine. Some preferred it over modern medicine, as they believed modern medicines to be harmful chemicals, while traditional medicine is natural, and therefore harmless. Others were cautious with herbs, as safe and effective dosage is unknown. The majority preferred to use both traditional and modern medicine, as traditional medicine is safe and accessible, and modern medicine failed to solve a number of their infertility problems.

2. Doctor shopping

Some participants would visit more than one infertility doctor for the same complaint, during the same time period. Participant 8 used to seek four different doctors' opinions before any procedure, to make sure it was the correct decision. This patient had recurrent pregnancy loss, and discovered she was not examined properly, which eventually cost her a lot of money in diagnosing and treating the cause. Participant 12 was following up with an infertility doctor, then decided to shift to another doctor after failed IVF, due to low sperm quality. The reason was a lack of honesty, as this participant knew

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indirectly after her failed IVF procedure there was a high possibility of IVF failure; however, the physician did not disclose that. Additionally, participants sought second opinions while still following up with their primary physicians because their physician did not give a contact number, provided inadequate information, or did not disclose all available options. Some women changed physicians, or even hospitals, due to failure to provide a clear plan from the start, failure to reach a diagnosis and order important tests, doctors' offensive behaviour, poor communication, or physical discomfort.

3. Stopping infertility care

Some participants stopped seeking infertility care, although they still needed it. Women can face many obstacles during infertility care, and they commonly try to overcome these obstacles to get pregnant. The major obstacle that led participants to stop seeking care was cost, which was described as 'horrible.' Other obstacles, such as lack of support and cooperation from husbands, also contributed, but did not lead to complete discontinuation.

'*Images and tests and so-on!! we paid a large sum of money! And not covered by insurance… Actually, the cost should not be huge. It should not be purely materialistic*', Participant 13, primary infertility.

4. Avoiding public hospitals and preferring expensive private care

Although cost was a major barrier to accessing infertility care, several participants surprisingly chose to seek care in the expensive private sector. The reasons included poor environment in government hospitals, difficulty booking appropriate appointments, and long wait times. An important factor was unavailability of infertility units and important services (e.g. IVF) in general government hospitals. Therefore, couples experiencing infertility received care in the general obstetrics/gynaecology clinics.

'*So, I never mind paying the blood of my heart (all what I have) to go to a place where I'm comfortable psychologically while I'm receiving care, in order to not end up with a bad experience or a bad smell in my memory (the bad smell in some low quality hospitals)*', Participant 5, primary infertility.

5. Seeking care from unqualified therapists, which could cause harm

Participants sought care from unknown individuals who posted on social media. Participant 10 followed a woman on Instagram who posted prescriptions related to an ovulation induction technique composed of three drugs. Participant 12 received an advertisement online from a person claiming to

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have medicines not available in Saudi Arabia that he could ship at a high cost. That medicine was not licensed by the FDA and not sold in pharmacies anywhere. Participant 7 visited an unlicensed massage therapist who claimed she could correct the position of one's womb. These behaviours were attributed to the failure of physicians to reach a diagnosis or successfully treat the problem. Furthermore, the unqualified individuals tended to communicate well, take a detailed history, provide adequate information, and were easy to access and highly responsive.

'Imagine, he asked me questions I'd never been asked by any of the doctors I'd visited here'!

Participant 12, primary infertility.

6. Seeking care despite dissatisfaction with services

Achieving some dimensions of PCIC ameliorated the absence of others, thereby encouraging participants to seek care, such as a doctor's competence and communication skills. Many participants visited an infertility care facility they did not like because they were looking for specific physicians. Thus, a good doctor's communication skills and competence supported seeking infertility care and encouraged participants to temporarily ignore physical discomfort.

DISCUSSION

In the current study, PCIC was defined across nine dimensions, from the perspectives of Arab women experiencing infertility. All participants agreed on four dimensions: accessibility, minimising costs, information and education, and staff attitudes and communication. The five remaining dimensions were staff competence, physical comfort, privacy, continuity and coordination of care, and psychological and emotional support. PCIC was found to have three major contributors: participants' demographics, patient experience with infertility care, and HSB.

Comparing these PCIC dimensions with those developed by Dancet and colleagues from across Europe (European PCIC-model) [14], we found them to be similar to some extent (Table 3). There were substantial differences, however. First, minimising cost was highly valued by our participants, but absent in the European model. Similarly, patient involvement in the European model was not mentioned by our participants. Second, prioritisation of the dimensions differed. For example, accessibility, a dimension agreed upon by all our participants, was among the least prioritised by European participants. Third, even dimensions included in both models showed some differences in

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preferences and needs between Arab and European groups. For example, concerning provision of information, our participants focused on deficient information during treatment at the health facility; however, the European model included the more ambitious addition of receiving information on media. These three differences reflect Arab women's low expectations, compared to European women. They mainly focused on unmet needs, which shaped the majority of PCIC definitions in our study.

Maslow's hierarchy of needs explains this pattern well [19]. It is a motivational theory comprising a five-tier model of human needs; needs lower in the hierarchy must be satisfied before individuals can attend to higher needs. These needs are divided into deficiency (basic) needs (physiological, safety, love and belonging, and esteem) and growth needs (self-actualisation). Self-actualised people use their full potential [19]. Figure 2 shows Maslow's hierarchy of needs, as adapted to PCIC. Notably, it was difficult to sort dimensions by need categories when adapting Maslow's hierarchy to PCIC, as each dimension could include a mixture of deficiency and growth needs. For example, information provision could be a basic need (e.g. how to use a medication) or a growth need (e.g. detailed knowledge on IVF procedures to facilitate decision-making). The hierarchy indicates that participants focused on deficiency needs, as all nine dimensions are within the deficiency needs zone and did not reach self-actualisation. IDI transcripts showed low expectations among participants, with few exceptions. Based on Maslow's hierarchy, this indicates participants' deficiency needs were not covered, and they continued to struggle to receive infertility care. Thus, PCIC is expected to help Arab women experiencing infertility satisfy their deficiency needs and become motivated to achieve self-actualisation, thereby empowering them to participate in infertility care.

The current study found that PCIC definition was shaped by the patient experience with infertility care. This finding indicates that this definition is dynamic and not static. The patient can give different preferences if the concept was explored at different periods of time.

To the best of our knowledge, this is the first study that showed a possible association between PCC and HSB. Generally, seeking infertility medical care has been shown to relate to prior experience with doctors [20]. In line with our findings, self-medication has been associated with some dimensions of PCC, including accessibility (especially lack of insurance coverage) [21 22], knowledge [23], physical comfort [23], and dissatisfaction with health care providers [18]. Huppelschoten and colleagues found no relation of PCIC with drop-out [24]. Our findings suggested the opposite, as PCIC was found to

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relate to discontinuation of treatment and changing doctors or hospitals. Sansone and Sansone supported that inconvenient clinician factors promote doctor shopping [25]. Unlike other forms of HSB, we found that using traditional and spiritual treatments was related to beliefs and preferences over conventional medicine, in line with previous literature [20 26 27].

Limitations

Regarding limitations, our study was conducted in a single city. Collecting data from across Saudi Arabia, or more than one country in the Arab world, was infeasible due to a lack of funding. The current study highlighted the possible effect of PCIC on HSB; however, we could not prove this association due to the nature of qualitative research. Future quantitative studies are needed to confirm the association and, if proven, to consider HSB as an indicator of PCIC. We hope this study will prompt further research regarding PCIC in the Arab World, thereby improving the quality of infertility care and quality of life for women who experience infertility. Our study developed a list of PCIC dimensions and items, but did not include a tool to measure PCIC. Thus, further work is recommended to develop a validated tool for measuring PCIC from Arab patients' perspectives.

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Author Contributions

HHW, TATI, and SBI contributed to the study design. HHW and AJK collected the data. HHW, TATI, SBI, and AJK performed data analysis and interpretation. HHW wrote the first draft of the article and all authors contributed to subsequent revisions.

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Competing interests None declared.

Patient and public involvement Patients were involved in the conduct, and reporting of this research. Refer to the Methods section for further details.

Patient consent for publication Not required.

Ethics approval The study proposal was reviewed and approved by the Human Research and Ethics Committee at Universiti Sains, in Malaysia (No. USM/JEPeM/15020056, Date 03/11/2015). The study was performed in accordance with the ethical standards as laid down in the 1964 Declaration of Helsinki and its later amendments. Informed consent was obtained from all participants. Respondents' privacy and confidentiality were assured.

Provenance and peer review: Not commissioned; externally peer reviewed.

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Data availability statement: Extra data is available by emailing HHW.

Supplementary data

Supplementary file 1, in-depth interview guide

Supplementary file 2, patient's experience mapping, an example

Supplementary file 3, COREQ checklist for qualitative research

Supplementary file 4, quotations showing participants' definitions of patient-centred infertility care (PCIC) and dominant events in each patient's experience

Figures:

Fig.1 Diagram shows the interaction between PCIC definition and patient experience, psychosocio-demographic features, and health seeking behaviour (rectangles)

Fig.2 Maslow's Hierarchy of Patient-centered infertility care (PCIC)

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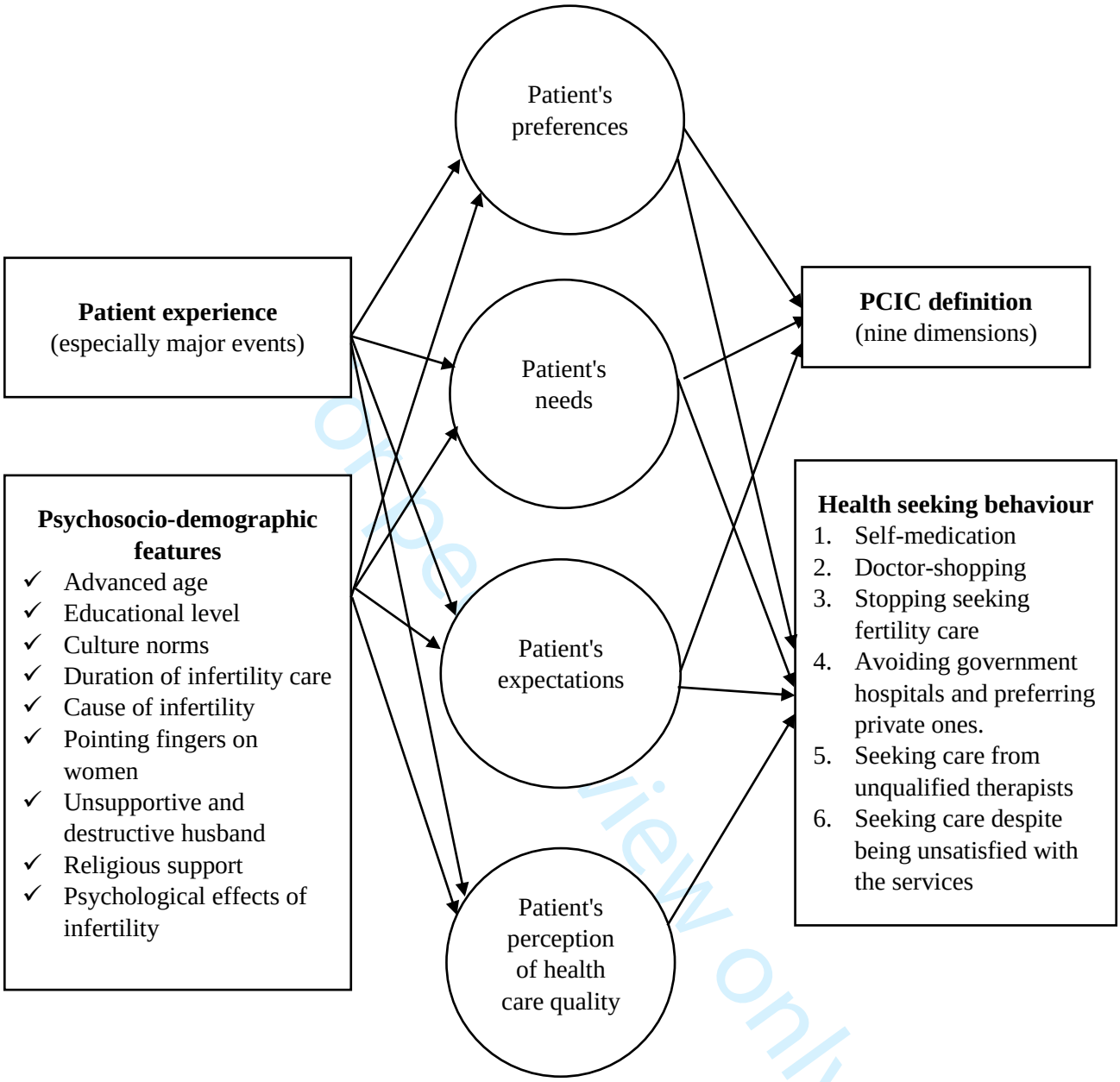

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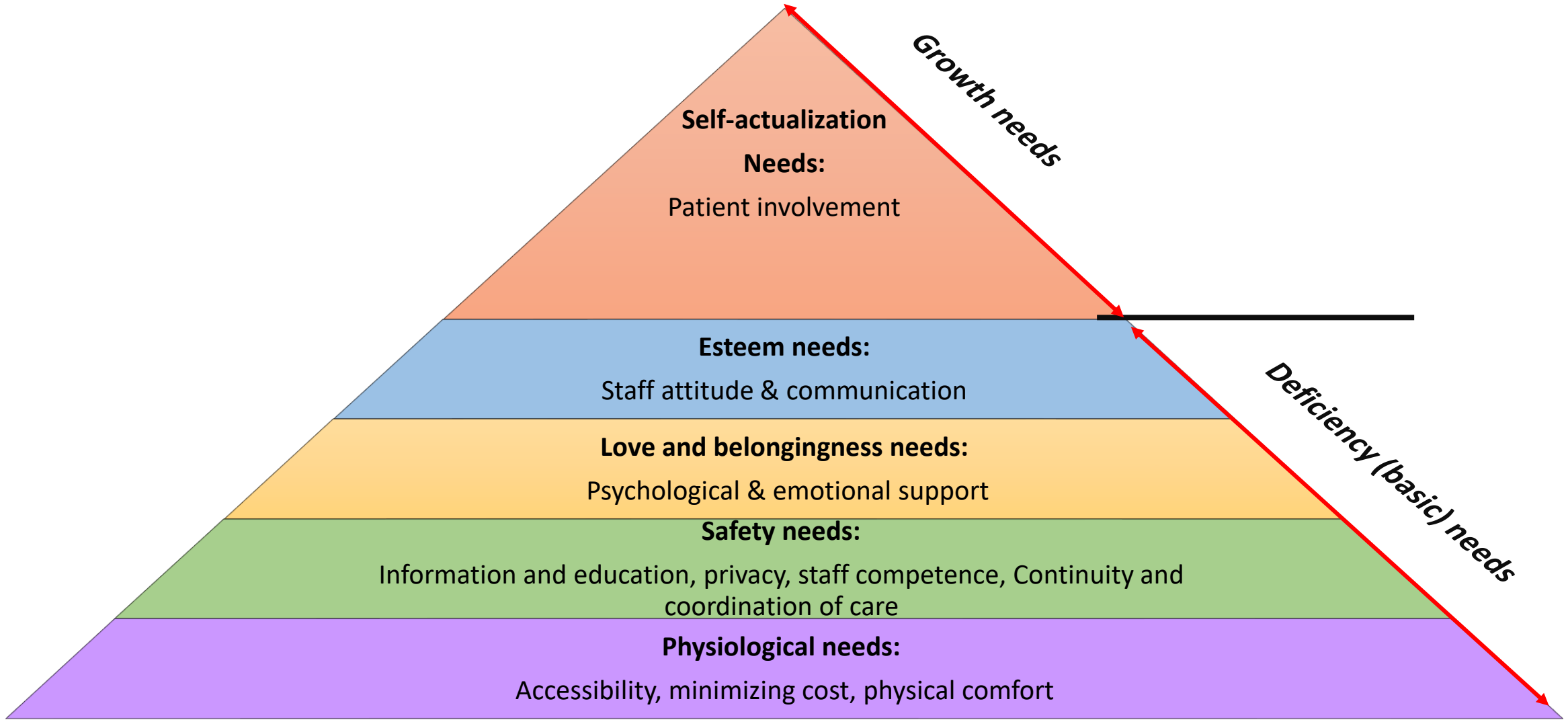

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1

Title Exploring patient-centered infertility care among Arab infertile women: a qualitative study

Journal name: BMJ Open

Authors

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2

In-depth Interview Guide

Background Information

ID:	
Personal data	
Age (years):	Sex: ☐ Male ☐ Female
Education: ☐ Illiterate ☐ Primary ☐ Secondary ☐ Diploma ☐ Bachelor ☐ Master or higher	
Occupation	Address
Infertility-related data	
Duration of marriage (months):	Duration of infertility (months):
Duration of seeking fertility care (months):	No of pregnancies:
No. of live children:	Cause of infertility:
Are you (your wife) pregnant now? ☐ Yes ☐ No	
Where you had received fertility care; please write the name of clinic and hospital. If you sought more than one clinic, please mention them chronologically and specify the period in front of each. …… …… …… ……	

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3

In-depth Interview Guide (con'd)

Introduction Key Components	✓ Participant name and personal data ✓ Research information ✓ Signature of consent
Questions	1. What types of infertility medical care have you received? 2. What characteristics of infertility care, would you recommend be sustained and/or introduced? Please provide a justification for your response. 3. What are the things you have missed in your infertility care? 4. What do you think will work well in increasing utilization of infertility care? Please explain 5. How would you recommend for future infertility care? 6. If all what you have recommended above are made available, would you seek other non-medical source of care for infertility? Please justify 7. What are the elements of patient-centered fertility care from your point of view? Please elaborate N.B. -Probes should be used as needed.
Closing Key Components	✓ Is there anything more you would like to add? ✓ I'll be analyzing the information you and others gave me. I'll be happy to send you a copy of the result, if you are interested. ✓ Thank you for your time.

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4

دليل المقابلة المتعمقة

مكونات المقدمة الرئيسية	✓ البيانات الشخصية ✓ معلومات حول البحث ✓ التوقيع على الموافقة
الأسئلة	١. ماهي أنواع الرعاية الطبية لتأخر الحمل التي خضعت لها من قبل؟ ٢. ماهي مواصفات الرعاية الصحية لتأخر الحمل التي توصين أن نبقي عليها أو نستحدثها؟ أرجو تبرير جابتك ٣. ماهي الأشياء التي افتقدتها أثناء تلقيك الرعاية الطبية لتأخر الحمل؟ ٤. ماهي الأشياء التي تعتقدين أنها ستكون فعالة في زيادة الاستفادة من رعاية تأخر الحمل؟ أرجو الشرح ٥. كيف تنصحين للرعاية الطبية لتأخر الحمل في المستقبل؟ ٦. إذا تم توفير كل ما أوصيت به أعلاه, هل ستلجئين لوسائل أخرى غير طبية لعلاج تأخر الحمل؟ أرجو التبرير ٧. ماهي مكونات الرعاية المتمركزة حول المريض من وجهة نظرك؟ أرجو التفصيل ملاحظة: - ستستخدم التحقيقات حسب الحاجة
مكونات الخاتمة الرئيسية	✓ هل هناك أي شيء تودين إضافته؟ ✓ سأقوم بتحليل المعلومات التي أعطيتني أنت و غيرك من المشاركين. سأكون سعيدا لأرسل لك نسخة من النتيجة، إذا كانت تهمك. ✓ شكرا لك على وقتك

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Title: Exploring patient-centered infertility care among Arab infertile women: a qualitative study

Journal: BMJ Open

Authors: Hana Hasan Webair1,2*, Tengku Alina Tengku Ismail3, Shaiful Bahari Ismail1, Azza Jameel Khaffaji4

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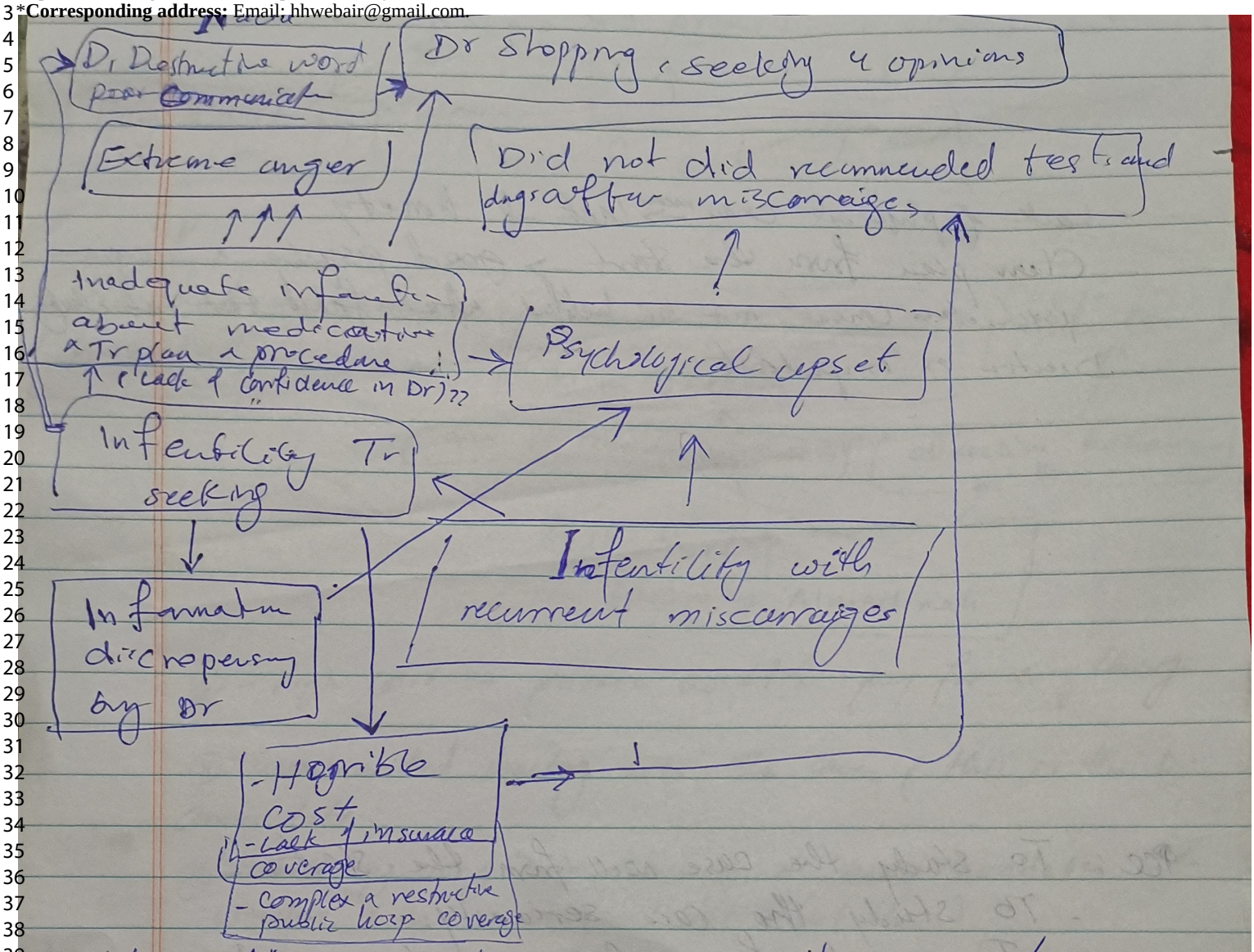

Important notes

- All are negative no many positive points
- Loss of confidence due to lack of information Quotes: "It was possible to tell me we will keep you under observation ....."
- Lack of clear plan from the start, lack of studying the case from all aspects from the start.
- Horrible price
- Appointments → No walk-in → Walk-in should be accepted
- Direct contact with Dr through personal mobile.
- Online consultations esp. for big names Dr
- Insurance should cover at least part of the cost

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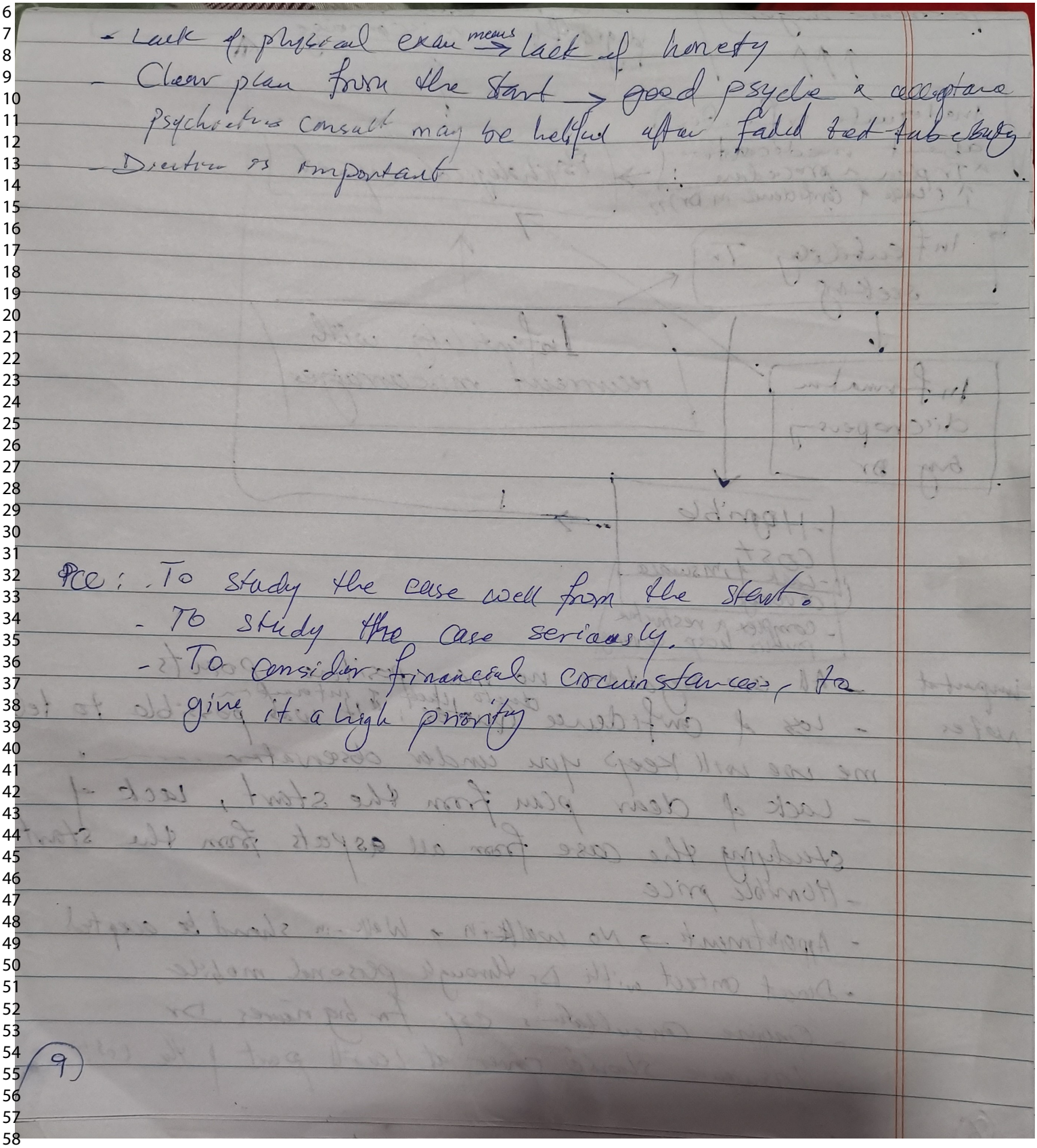
- Lack of physical exam means → lack of honesty
- Clear plan from the start → good psycle & acceptance
psychiatric consult may be helpful after failed 3rd lab study
- Direction is important
PCC: To study the case well from the start.
- To study the case seriously.
- To consider financial circumstances, to give it a high priority
9

Title Exploring patient-centered infertility care among Arab infertile women: a qualitative study

Journal name: BMJ Open

Authors

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Panel: Quotations showing participants' definitions of patient-centred infertility care (PCIC) and dominant events in each patient's experience	
'we lacked health awareness. I may enter to do dental x-ray; they do not tell me you should cover your body with a special cover. So, if you don't know, you will not find guidance. Information and awareness raising are first. Awareness raising and stop putting everything on the woman'. **Participant 1: 30- 35 years age group, primary infertility, bachelor's degree, male factor** Doctors treated her as the cause for infertility and did not investigate her husband. As a result, she was exposed to unnecessary treatment for nine months, with no benefit. Finally, they performed a semen analysis and diagnosed male-factor infertility. The option of IVF was not discussed with her, and the doctor instead prescribed medication. She searched for a second opinion and knew the best option for their case was IVF.	*'Regarding infertility treatment, case study…means to study all aspects…Regarding diet, psychological comfort, the patient who does something which causes the problem...I mean, I should revise the patient's case, the routines in her life. There are fixed essentials in a patient's life that could be wrong and could be the cause behind her problem'.* **Participant 2: 35-39 years age group, secondary infertility, 3 daughters, bachelor degree, endometriosis.** She had three daughters from her first marriage spontaneously. After her second marriage, she developed endometriosis, with recurrent cysts and adhesions, which caused pain and infertility. She was very upset by this new issue in her life, and how the modern medicine did not find the cause behind it. She lived in a city away from Jeddah, with an unsupportive husband who gave up on operations and follow-up. She had very poor mental health.
'I feel it should be the same as when I delivered for the second time. The doctor welcomed me warmly! She asked me what type of delivery I'd prefer to have—this should be your choice. I told her I wanted to deliver normally. She told me, I will give you a paper to sign, and I will do my best to deliver you normally. If there is even one percent risk for you or the baby, excuse me, I will shift you to caesarean. I mean, she explained everything for you! When she came to do anything, she explained it for me—I will do so and so for this purpose. Although I did not understand their language—it was in America—everything was by sign language. I mean, there was a big	*'It is clear from the words that it means when the doctor becomes interested in his patient, what the patient likes and prefers. As I mentioned, to treat the patient as a human, the way he is comfortable, without forcing him. To give him his due. For example, if there are two medicines with the same effect, I should prescribe what the patient is comfortable using. To deal with the patient in a humanitarian, not materialistic way. For example, when I gave birth to my daughter, I wanted to give the doctor who delivered her a gift, because she supported and helped me. People says it is her duty! But the doctor who knows his job makes people feel comfortable'.*

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difference in her attitude, from my first delivery. This is patient-centred care'. **Participant 3: 25- 39 years age group, secondary infertility, 2 sons, bachelor's degree, ovulatory cause** Complained of inadequate information, especially regarding medication, and the absence of collaboration in management planning. She needed to ask her physician about medication, but could not reach her, due to having no method for communication. She looked for a second opinion (her friend was a doctor), who gave her a plan that was different from her doctor's plan. She was confused and unsatisfied.	**Participant 4: 35- 39 years age group, secondary infertility, son & daughter, high school diploma, hyperprolactinemia** She did not like medication or hospital work-ups, and preferred natural remedies. She started complementary medicine, and when it failed, she sought medical care. She had irregular visits, then she stopped seeking care due to lack of appropriate appointments, very expensive treatment, and lack of support from her husband. Her husband blamed her for the infertility, although both of them had children from their first marriages, and refused semen analysis, so her doctor refused to treat her. One doctor told her she was the cause of the infertility, and another one told her after all that, you want to get pregnant (2 kids and 34 years old)!
'If we make treatments personalised, if we talk about the patients themselves... my doctor was treating me, and told me, "you are overweight, so you should drink a lot of water", talking about me personally', **Participant 5: 25- 29 years age group, primary infertility, bachelor's degree, ovulatory cause** She thought obesity was the cause of her infertility. She tried treating this in a public hospital, but discontinued because they dealt with her disease-wise, not as a person. She started obesity treatment on her own, for herself and her husband. She went to a doctor in a public hospital, despite the very poor environment and services, and the presence of trainees, only because that doctor personalised her treatment.	*'The doctors and the nurses themselves should be good. Also, the place, the hospital itself, prepares you. The cleanliness of the hospital…The devices should be advanced enough, some hospitals are really….that's all'.* **Participant 6: 20-24 years age group, primary infertility, secondary school, unexplained infertility** She had a bad experience with materialistic doctors and no health benefits. She also had bad experiences with public hospitals that lacked facilities and were a poor environment. She shifted to a private hospital, although it was expensive. The cause of her infertility remained unknown until finally, she visited a doctor who recommended a scope for the first time. She was sad nobody told her about it before!

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'The first thing is to take care of patients and treat them. Treatment, for example. I mean, to care about treatment and medications, what is the patient's problem—from what? Yes, they should know what the patient's problem is and treat it'. **Participant 7: 40-45 years age group, secondary infertility, no living children, secondary school, male factor** The cause was unknown, apart from her age. Then, her husband developed male factor infertility after one failed IVF. She followed up in both public and private hospitals. She used traditional medicine when doctors did not diagnose the cause of her infertility.	*'To study the case well from the start. To study the case seriously! Not only try, try haphazardly, and that's it. No! To study the case seriously! To consider the financial circumstances. To give it high priority, not only, "this what we have, do it"'.* **Participant 8: 40-45 years age group, secondary infertility, 2 living children, bachelor's degree, unexplained infertility** She had recurrent miscarriages after two births. Now, she is over 40. She received conflicting opinions from different doctors. Finally, after six miscarriages and getting older, she knew the best option in her case was to test the abortus for genetic disorders. However, because it was not done, she could try IVF with genetic testing for the embryos. She knew it would cost around 30,000 SR, which is out of her ability. So, she does not trust doctors and would habitually seek four different doctors' opinion before starting any treatment.
'Do you mean all of this could be centred on me? So, the patient should have interests, have awareness, have… right? Aha! to.. of course, you cannot control that, why? Because there will be overload, so doctors will not be able to cover it all. So, whatever I tell you, it will not be covered fully; therefore, whatever you do for me I will not see anything! Aha! It depends on the patient and complaint, you know? Apart from that, the most important thing is psychological preparation'. **Participant 9: 35-39 years age group, secondary infertility, 2 daughters, bachelor's degree (medical staff), undiagnosed infertility (husband refused semen analysis)** Her husband is very unsupportive and destructive. She has had poor experiences with the female doctors and good	*'The term means to make appointments booking easily available and to listen to me. Yes! And to listen to me, I mean to hear me well, and my interests, and so on. I mean the same thing—the discrimination. To avoid discrimination when dealing with patients'.* **Participant 10: 30-35 years age group, secondary infertility, daughter & son, literate, ovulatory cause** She had secondary infertility after her first daughter, and was on ovulation induction for a long time. First, she went to doctors for that purpose. Then, because it is difficult to find appointment soon, and this caused missing the chance for following ovulation and intercourse timing, thereby delaying treatment, she started taking medication illegally and following ovulation in any polyclinic nearby. She had a lot of questions and was in a hurry to get pregnant, as she had marital instability and her social norms meant

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experiences with male ones, regarding communication skills. She felt men are easier to understand.	she should have many children. Doctors gave up answering her questions. She had ovarian cysts and two operations.
'The most important thing is the behaviour of the doctor, also the receptionist, and the hospital as a whole. The nurses and all should serve the patient. I mean, some of them, their behaviour is as if you are coming to panhandle. As if they are not employed and receiving salaries! They should serve us and others. This is their job'. **Participant 11: 30-35 years age group, primary infertility, bachelor's degree, tubal factor?** She lived far away, but chose to come to Jeddah, because her friend had a positive experience. She started in government hospitals, then after long wait times and offensive behaviour from one doctor, she shifted to a private hospital, although it was very expensive.	*'First should be to pay attention to the patient's psychological status. To pay attention to the patient's feelings. I mean, do not destroy patients. For example, if there is no effective treatment! Or if the sperm is of no value! This sometimes destroys the patient'.* **Participant 12: 25-29 years age group, primary infertility, high school diploma, male factor** She had failed intrauterine insemination and IVF attempts. She discovered afterwards that her doctor did not disclose to them the male factor or low success rate. She planned to change to another doctor, but could not pay the cost. She contacted an unlicensed therapist through Instagram who claimed he had medicines for sperms count and quality. She was so happy with his way of communication and that he listened to her whole history that wanted to continue with him.
'I hope there is something like this. It is awesome! To not be purely materialistic. Actually, the cost should not be huge. The situation should not be purely materialistic. I mean, I have to pay for anything to be done for me! For example, for the psychologist, I need to pay a large sum of money! For each visit he sets with me, I will pay?! No'. **Participant 13: 40-45 years age group, primary infertility, secondary school, tubal factor** She started medical treatment, but it failed. It was found that her fallopian tubes were blocked. IVF was recommended, with some procedures beforehand. She could not do it, due to cost. She complained of social pressure and blame. She did not understand doctors well because they spoke English.	*'The care, by all means, is patient-centred. There is a discussion between the doctor and patient. The doctor provides what he has, if the patient does not like something, the patient should say so. Yes. So, it depends on the patient. If the patient discusses matters with the doctor, they will find an answer. But if the doctor spontaneously asks the patient what do you want? No! Here, I will be in doubt—is this really a doctor'?* **Participant 14: 25-29 years age group, 1ry infertility, bachelor's degree, ovulatory cause** She had an ovarian cyst with pain and dyspareunia. She started with a doctor who treated her with medications that showed no benefits. She then changed to another doctor, who removed the cyst surgically. She went to a third doctor for infertility, who gave her a clear plan from the start (still ongoing).

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COREQ (COnsolidated criteria for REporting Qualitative research) Checklist

A checklist of items that should be included in reports of qualitative research. You must report the page number in your manuscript where you consider each of the items listed in this checklist. If you have not included this information, either revise your manuscript accordingly before submitting or note N/A.

Topic	Item No.	Guide Questions/Description	Reported on Page No.
Domain 1: Research team and reflexivity			
Personal characteristics			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?	
Credentials	2	What were the researcher's credentials? E.g. PhD, MD	
Occupation	3	What was their occupation at the time of the study?	
Gender	4	Was the researcher male or female?	
Experience and training	5	What experience or training did the researcher have?	
Relationship with participants			
Relationship established	6	Was a relationship established prior to study commencement?	
Participant knowledge of the interviewer	7	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	
Interviewer characteristics	8	What characteristics were reported about the inter viewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	
Domain 2: Study design			
Theoretical framework			
Methodological orientation and Theory	9	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	
Participant selection			
Sampling	10	How were participants selected? e.g. purposive, convenience, consecutive, snowball	
Method of approach	11	How were participants approached? e.g. face-to-face, telephone, mail, email	
Sample size	12	How many participants were in the study?	
Non-participation	13	How many people refused to participate or dropped out? Reasons?	
Setting			
Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace	
Presence of non-participants	15	Was anyone else present besides the participants and researchers?	
Description of sample	16	What are the important characteristics of the sample? e.g. demographic data, date	
Data collection			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested?	
Repeat interviews	18	Were repeat inter views carried out? If yes, how many?	
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	
Field notes	20	Were field notes made during and/or after the inter view or focus group?	
Duration	21	What was the duration of the inter views or focus group?	
Data saturation	22	Was data saturation discussed?	
Transcripts returned	23	Were transcripts returned to participants for comment and/or	

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Topic	Item No.	Guide Questions/Description	Reported on Page No.
		correction?	
Domain 3: analysis and findings			
Data analysis			
Number of data coders	24	How many data coders coded the data?	
Description of the coding tree	25	Did authors provide a description of the coding tree?	
Derivation of themes	26	Were themes identified in advance or derived from the data?	
Software	27	What software, if applicable, was used to manage the data?	
Participant checking	28	Did participants provide feedback on the findings?	
Reporting			
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	
Data and findings consistent	30	Was there consistency between the data presented and the findings?	
Clarity of major themes	31	Were major themes clearly presented in the findings?	
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes?	

Developed from: Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357

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Manuscript Title Exploring patient-centered infertility care among Arab infertile women: a qualitative study

Journal: BMJ Open

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Patient-centred infertility care among Arab women experiencing infertility: a qualitative study

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TITLE Patient-centred infertility care among Arab women experiencing infertility: a qualitative study

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ABSTRACT

Objective: The current study aims to define patient-centred infertility care (PCIC) from the perspective of Arab women with infertility.

Design: Semi-structured in-depth telephone interviews.

Setting: Hospitals providing infertility care, Jeddah, Saudi Arabia.

Participants: Arab women who received infertility treatment during the six months preceding the interview at any hospital in Jeddah, Saudi Arabia. Interviews were conducted with Arab women experiencing infertility from January 2017 to December 2018**.** A purposive sample of 14 women were included in the final analysis with maximum variation.

Results: Participants highlighted nine important PCIC dimensions. Of these, four were agreed upon by all participants: accessibility, minimising cost, information and education, and staff attitudes and communication. The remaining five dimensions were staff competence, physical comfort, privacy, psychological and emotional support, and continuity and coordination of care. The concept of PCIC was related to three major contributors: participants' demographics, patient experience with infertility care, and health seeking behaviour (HSB).

Conclusions: The current study provided nine PCIC dimensions and items, which can guide efforts to improve the quality of infertility care in Arab countries in two ways: first, by raising infertility care providers' awareness of their patients' needs, and second, by developing a validated tool based on the dimensions for measuring PCIC from Arab patients' perspective. Clear differences between the Arab and the European PCIC model were found. Our findings concluded that women continued to exhibit basic unmet needs.

Keywords: Patient-centred care, infertility, women's health services, Arab world

ARTICLE SUMMARY

Strengths and limitations of this study

- This study defined for the first time the concept of patient-centred infertility care from Arab women's perspective by using a qualitative approach.
- The study included women only, so the applicability of this concept to males is not appropriate.
- Our study was limited by being conducted in a single city; therefore a multi-centre, cross-cultural study may provide results which are more generalisable.

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INTRODUCTION

Infertility is a worldwide public health concern.[1] Globally, the estimated infertility rate ranges from 3·5% to 26·4%; however, the burden of infertility is higher in developing countries where 1:4 couples experience fertility problems in their reproductive lives.[2-4]

The infertility care journey is invariably long and emotionally and psychosocially stressful.[5 6] Couples experiencing infertility frequently face difficulty in accessing infertility care—especially assisted reproductive technologies—as access varies widely across countries and regions, and is lowest in lower and middle income countries.[7]

Previously, conceptualisations of quality of infertility care focused on outcome measures.[8 9] However, this focus is changing, as patient-centred care (PCC) is being increasingly recognised as important for high-quality infertility care.[10-12] Patient-centred infertility care (PCIC) was studied among European couples experiencing infertility,[13 14] and the following 10dimensions were identified: information provision, competence of clinic and staff, continuity and transition, coordination and integration, accessibility, physical comfort, attitude of and relationship with staff, communication, patient involvement and privacy, and emotional support.[10 13] These dimensions provided the basis and structure of the Patient-Centredness Questionnaire-Infertility, validated for use among European populations.[12]

A literature review conducted in 2017 failed to define PCIC from the perspective of Arab patients experiencing infertility; thus, the question remained unanswered.[15] What was validated in Europe might not be the case in the Arab world due to regional and cultural differences believed to affect infertility care, including counselling and treatment modalities.[16] Thus, we aimed to define PCIC from the perspective of Arab women with infertility.

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METHODS

Design

This is a qualitative study using in-depth interviews (IDIs) to define PCIC from the perspective of Arab women experiencing infertility. PCIC is defined as infertility care that considers women's preferences, needs, and values, and entails their participation in all clinical decisions.[10] Ethical approvals were provided by the IRB of the Department of Medical Research and Studies; the Department, Directorate of Health Affairs, Ministry of Health, Jeddah, Saudi Arabia (number A00306); and the Universiti of Sains Malaysia (number USM/JEPeM/15020056, Date 03/11/2015). Continuing review application of the protocol was carried out yearly before data collection, which was conducted during the period 2017-2018. Written informed consent was obtained from all participants.

Study population

Between January 2017 and December 2018, IDIs were conducted in Jeddah, Saudi Arabia. Inclusion criteria were Arab women who had received medical treatment for infertility during the six months preceding the interview, at any hospital in Jeddah. A purposive sample of 14 women were recruited, with maximum variation. The motive behind maximum variation sampling was to gain greater insight into PCIC by viewing it from different angles. Variations included age group, level of education, occupation, duration of marriage and infertility, infertility type, number of living children, treatment used, health facility visited, and duration of seeking infertility care. Participants were recruited purposefully until data saturation was reached and no new themes emerged.

Data collection and analysis

In-depth interviews were conducted via telephone. Researchers have found no real difference in the quality of data or the published papers when using telephone interviews compared to face-to-face interviews.[1] In addition, telephone interviews have many advantages, including being less intrusive, more cost effective, less time consuming, and involving less interview tension.[2] During the participant recruitment phase, the invited women reported that they would prefer telephone interviews over face-to-face ones. This interview method provided more anonymity and autonomy as the participants were asked to mention their given name only and they could choose the time, and the phone number to be called on. The length of the IDIs ranged from 45 to 90 minutes. All IDIs were

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conducted by a female researcher, who is a family physician with experience in qualitative data collection (HHW). An interview guide was used to collect data flexibly. Initially, the researcher introduced herself as a researcher and family physician interested in patient-centred care. Then, each participant was provided with a consent form, which included a clear explanation of the aim of the study, and was asked to sign the form if he/she agreed to participate. The IDI guide consisted of two parts; part one assessed participants' demographics, and part two included a question regarding medical care received, followed by six open-ended questions regarding PCIC (Supplementary file 1). Each interview was audio recorded, transcribed verbatim, translated from Arabic to English, then imported into NVivo version 12 for analysis.

Inductive thematic analysis: Inductive coding thematic analysis was applied to describe, compare and relate findings, as patient centredness had not been defined from Arab patients' perspective. The first step in the analysis was reading and re-reading the transcripts several times to become familiar with emerging data. At this stage, notes were written by hand, summarising the main points and our initial impressions. These notes focused on mapping out patients' experiences with fertility care received and their definitions of PCIC. Next, HHW and TATI used line-by-line coding independently for each IDI. Authors HHW and TATI examined the data to identify and agree on common themes, which were analysed independently, whilst continuously developing and modifying codes. When we completed coding for five IDIs, findings were discussed and modified before moving forward. Discrepancies were discussed until consensus was reached. If consensus was not reached, that point was discussed with the third author (SBI). Then, codes were categorised into preliminary subthemes and themes.

Data saturation was reached on completion of fourteen IDIs, yielding148 codes. Preliminary themes were continuously reviewed and modified until we developed the final themes. Matrix queries produced by NVivo were used to display the frequency of codes occurring within the text, or of codes and participants' characteristics. This matrix enabled us to assess the degree of agreement among participants and the nature of the associations.

Four methods were adopted to enhance validity. First, different aspects of the same concept were assessed. The IDI guide included six questions about PCIC; however, they were worded differently asking about participants' positive and negative perceptions of care experience, what they needed from infertility care, what would be an optimal situation, and, finally, a direct question about participants'

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definitions of PCIC. Second, source triangulation was used by ensuring maximum variations in the sample to explore PCIC from different viewpoints. Additionally, two gynaecologists were asked about concerns in infertility care expressed by participants, such as waiting times and financial aspects. In addition, after completion of data analysis, the PCIC dimensions that emerged from the current study were compared with those identified by European participants, the only available PCIC dimensions from patients' perspectives before our study. Third, analyst triangulation was applied, with three analysts involved in reviewing the findings. Fourth, respondents' validation was sought. After data analysis, we sent participants a summary of the PCIC dimensions and their items. All agreed that the dimensions they preferred were included. Two respondents stressed avoiding long waiting times and providing appropriate appointments for the purpose of follow-up visits. The results are reported according to the Consolidated Criteria for Reporting Qualitative Research (COREQ).[17] (Supplementary file 2)

Patient and public involvement Patients were involved in the conduct and reporting of this research. Please refer to the Methods section for further details.

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RESULTS

Table 1 shows participants' demographics. Thematic analysis yielded three themes: (1) PCIC dimensions, (2) PCIC definition and patient experiences, and (3) PCIC and health seeking behaviour (HSB). The third theme included six subthemes. As shown in Figure 1, there was an interaction between participants' definitions of PCIC and patient experience, HSB, and their sociodemographic characteristics.

Table 1: Characteristics of participants involved in in-depth interviews (n=14)

Participant characteristics		**Number(%)**
Age, year	25-	5 (35·71%)
	30-	3 (21·43%)
	35-	3 (21·43%)
	40-45	3 (21·43%)
Residency	Jeddah	10 (71·43%)
	Out of Jeddah	4 (28·57%)
Duration of marriage, year	1-	7 (50·00%)
	5-	3 (21·43%)
	10-	1(7·14%)
	15-20	3 (21·43%)
Duration of infertility, year	1-	7 (50·00%)
	3-	5 (35·71%)
	6-	1 (7·14%)
	9-	1 (7·14%)
Duration of seeking infertility care, year	1-	8 (57·14%)
	3-	4 (28·57%)
	6-	2 (14·29%)
Number of living children	0	8 (57·14%)
	1or 2	5 (35·71%)
	3 or more	1 (7·14%)
Type of infertility	Primary	5 (35·71%)
	Secondary	9 (64·29%)
Pregnant now	Yes	2 (14·29%)
	No	12 (85·71%)
Type of treatment used	Medical (OI*, hyperprolactinemia)	13 (92·86%)
	IUI†	1 (7·14%)
	ICSI/IVF‡	3 (21·43%)
	Surgical	6 (42·86%)

*OI; ovulation induction, †IUI; intrauterine insemination, ‡ICSI/IVF; Intracytoplasmic sperm injection/in-vitro fertilization.

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PCIC dimensions

Nine PCIC dimensions were identified from 14 IDIs. Table 2 summarises the dimensions and each of their items, ordered following a logical stream, similar to what patients experience during infertility care.

Table 2: Patient-centred infertility care (PCIC) dimensions from the perspective of Arab women experiencing infertility

PCIC dimensions	PCIC items
Accessibility	Availability of appropriate appointments
	Ease of access to the health care facility
	Smoothness of the process of booking appointment, registration & workflow
	Justice in handling appointments & patient access
	Providing easy access to doctors through phone & online consultations
	Short waiting time
	Vacancy (no overcrowding)
Minimising cost	Covering infertility care cost by insurance
	Provision of infertility management in public sector free of charge
	Providing infertility care at reasonable, affordable cost
Physical comfort	Cleanliness
	Comfortable environment
	Assistance and provision of care
	Pain avoidance and relieve
	Single dose, less frequent medication doses
Privacy	Providing care in special department for women & infertility
	Providing female doctors or examiners
	Avoiding over or unnecessarily exposing intimate parts of patient's body
	Considering differences in privacy mean from patient to another
	Ensuring minimal interruption and number of people in, no men or other patients
	Taking patient permission before allowing more people in
	Preferring nobody knows about patient's infertility issues
	Considering differences in the preferences regarding husband involvement
Staff attitude and communication	Treating patient and other staff with dignity and respect
	Staff truthfulness
	Avoiding materialistic behaviour
	Practicing medicine in love and dedication
	Being so patient
	Religious approach
Staff competence	well-known doctors
	Proper and accurate evaluation; history, examination and investigations as needed
	Understanding the patient fast and well
	Providing diagnosis and curative solutions
	Avoiding medications with bad side effects
	Providing comprehensive and personalized care

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	Qualification

(Table 2 continues on next page)

PCIC dimensions	PCIC items
Information and education	Giving and taking, encouraging discussion and negotiation
	Providing relevant information about the patient status, progress, and prognosis
	Disclosure and clarification of all treatment options
	Providing information on processes of care before each step, what to expect before, during and after procedures, then home care, plan of care, and follow up
	Informing patient about the use, expected effects, and possible side effects before starting treatment
	Providing relevant information with adequate explanation
	Talking to patients with simple understandable language
	Welcoming patient questions and providing answers thought health care journey.
	Raising health awareness and education through school education, doctors in clinics, and campaigns
	Considering the patient's long experience as an expert in her case
Psychological and emotional support	Listening to patients
	Considering the patient's personal situation
	Preparing patient psychologically throughout her treatment journey
	Giving patient realistic hope
	Avoiding using destroying words or attitude, or pointing finger at the patient
	Ensuring ongoing support and motivation
Continuity and coordination of care	Studying the patient case well including proper documentation and up to date file review
	Treating couple as one case
	Developing and sharing detailed plan of care from the start
	Ongoing planning, follow up and coordination of care hand on hand with the patient based on health situations and patient needs
	Providing follow up with the same doctor
	Including doctors from same specialty and other specialties as needed
	Facilitating the shortest treatment journey
	Encouraging lady's check-up before marriage

All participants mentioned four dimensions as important elements of PCIC: accessibility (short waiting times), minimising cost (providing infertility care at a reasonable, affordable cost), information and education (providing relevant information with adequate explanation), and staff attitudes and communication (treating patients and other staff with dignity and respect). Information from obstetricians/gynaecologists supported participants' perspectives regarding waiting times and costs. Despite being noted as important dimensions, participants' preferences varied regarding maximum waiting times, relevant information, and privacy during infertility care. These preferences were affected

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to some extent by participants' educational level, infertility care experience, and marital relationship quality. Table 3 compares these dimensions with the European PCIC model.

Table 3: Comparison between the Arab and European Patient-centred infertility care (PCIC) dimensions

Arab PCIC dimensions	European PCIC dimensions
1. Accessibility	1. Accessibility
2. Minimizing cost*	..
3. Physical comfort	2. Physical comfort
4. Privacy	3. Patient involvement* and privacy
5. Staff attitude and communication	4. Attitude of and relationship with staff 5. Communication
6. Staff competence	6. Competence of clinic and staff
7. Information and education	7. Information provision
8. Psychological and emotional support	8. Emotional support
9. Continuity and coordination of care	9. Coordination and integration, 10. continuity and transition

*Indicates the dimension mentioned in one model only

PCIC definition and patient experience

When asked to define PCIC, participants provided short definitions focused on a few points, although they mentioned much more during the preceding questions about their infertility care experience. The panel (Supplementary file 3) shows participants' definitions of PCIC and summarises each participant's experience.

Most participants had a dominant issue during infertility care. These issues were related to the medical care itself or sociodemographic circumstances. Participant experience shaped participants' definitions of PCIC the most, as shown in the panel.

PCIC and HSB

PCIC dimensions influenced participants' HSB, as suggested by the following HSB subthemes.

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1. Self-medication

Participants practiced two methods of self-medication: obtaining non-prescribed medications, and using traditional or herbal medicines.

The first method is not a responsible form of self-medication, based on the WHO's definition [18]. One patient used ovulation induction medications (Clomiphene citrate tablets, Menotropin injections, and Choriomon injections) in high doses, reaching double the dosage prescribed by her physicians. All were prescription-only medications.

'I used to order images for myself for ovulation. I knew the size of the egg, they (doctors) got annoyed! Yes, I would get the image and ask for a trigger shot, because sometimes we had sex before meeting the doctor. I wanted to know, but sometimes you do not find the answer you are looking for…. Now I knew that if the egg was more than 15, I should take the trigger shot', Participant 10, secondary infertility

She did not ask her doctors to increase the dose, because she felt that they were 'fed up' with her many questions and requests. Additionally, appointments were far in the future; therefore, if she waited to meet her physician each time to obtain the prescription, she would have a very long treatment journey.

For the second method, most participants (12 out of 14) used traditional and/or herbal medicine during infertility care. Remedies included herbs, honey, cupping therapy (Hijamah), massage, and Qur'anic verses read to achieve improvement (Roqia). Participants had different attitudes towards this kind of medicine. Some preferred it over modern medicine, as they considered modern medicines to be harmful chemicals, while traditional medicine is natural, and therefore harmless. Others were cautious with herbs, as safe and effective dosage is unknown. The majority preferred to use both traditional and modern medicine, as traditional medicine is safe and accessible, and modern medicine failed to solve several of their infertility problems.

2. Doctor shopping

Some participants would visit more than one infertility doctor for the same complaint during the same time period. Participant 8 used to seek four different doctors' opinions before undergoing any procedure, to ensureit was the correct decision. This patient had recurrent pregnancy loss and discovered she was not examined properly, which eventually cost her a lot of money in diagnosing and

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treating the cause. Participant 12 was following up with an infertility doctor, then decided to shift to another doctor after failed IVF due to low sperm quality. The reason was a lack of honesty, as this participant knew indirectly after her failed IVF procedure that there was a high possibility of IVF failure; however, the physician did not disclose that. Additionally, participants sought second opinions while still following up with their primary physician because their physician did not give a contact number, provided inadequate information, or did not disclose all available options. Some women changed physicians, or even hospitals, due to failure to provide a clear plan from the start, failure to reach a diagnosis and order important tests, doctors' offensive behaviour, poor communication, or physical discomfort.

3. Stopping infertility care

Some participants stopped seeking infertility care, although they still needed it. Women can face many obstacles during infertility care, and they commonly try to overcome these obstacles to get pregnant. The major obstacle that led participants to stop seeking care was cost, which was described as 'horrible'. Other obstacles, such as lack of support and cooperation from husbands, also contributed, but did not lead to complete discontinuation.

'*Images and tests and so-on!! we paid a large sum of money! And not covered by insurance… Actually, the cost should not be huge. It should not be purely materialistic*', Participant 13, primary infertility.

4. Avoiding public hospitals and preferring expensive private care

Although cost was a major barrier to accessing infertility care, several participants surprisingly chose to seek care in the expensive private sector. The reasons included poor environment in government hospitals, difficulty booking appropriate appointments, and long waiting times. An important factor was the unavailability of infertility units and important services (e.g. IVF) in general government hospitals. Therefore, couples experiencing infertility received care in the general obstetrics/gynaecology clinics.

'*So, I never mind paying the blood of my heart (all what I have) to go to a place where I'm comfortable psychologically while I'm receiving care, in order to not end up with a bad experience or a bad smell in my memory (the bad smell in some low-quality hospitals)*', Participant 5, primary infertility.

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5. Seeking care from unqualified therapists, which could cause harm

Participants sought care from unknown individuals who posted on social media. Participant 10 followed a woman on Instagram who posted prescriptions related to an ovulation induction technique involving three drugs. Participant 12 received an advertisement online from a person claiming to have medicines that are not available in Saudi Arabia that he could ship at a high cost. That medicine was not licensed by the FDA and not sold in pharmacies anywhere. Participant 7 visited an unlicensed massage therapist who claimed she could correct the position of one's womb. These behaviours were attributed to the failure of physicians to reach a diagnosis or successfully treat the problem. Furthermore, the unqualified individuals tended to communicate well, take a detailed history, provide adequate information, and were easy to access and highly responsive.

'Imagine, he asked me questions I'd never been asked by any of the doctors I'd visited here!'

Participant 12, primary infertility.

6. Seeking care despite dissatisfaction with services

Achieving some dimensions of PCIC, such as a doctor's competence and communication skills, offset the absence of others, thereby encouraging participants to seek care. Many participants visited an infertility care facility they did not like because they were looking for specific physicians. Thus, a good doctor's communication skills and competence supported seeking infertility care and encouraged participants to temporarily overlook physical discomfort.

DISCUSSION

In the current study, PCIC was defined across nine dimensions, from the perspectives of Arab women experiencing infertility. All participants agreed on four dimensions: accessibility, minimising cost, information and education, and staff attitudes and communication. The five remaining dimensions were staff competence, physical comfort, privacy, continuity and coordination of care, and psychological and emotional support. PCIC had three major contributors: participants' demographics, patient experience with infertility care, and HSB.

Comparing These PCIC dimensions were similar, to some extent, to those developed by Dancet et al. from across Europe (European PCIC-model; Table 3).[14] There were substantial differences, however. First, minimising cost was highly valued by our participants, but absent in the European

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model. Similarly, patient involvement, which was included in the European model, was not mentioned by our participants. Second, prioritisation of the dimensions differed. For example, accessibility, a dimension agreed upon by all our participants, was among the least prioritised by European participants. Third, even dimensions included in both models showed some differences in preferences and needs between Arab and European groups. For example, concerning provision of information, our participants focused on deficient information during treatment at the health facility; however, the European model included the more ambitious addition of receiving information on media, such as DVD media. These three differences reflect Arab women's low expectations in relation to European women. They mainly focused on unmet needs, which shaped the majority of PCIC definitions in our study.

Maslow's hierarchy of needs explains this pattern well.[19] It is a motivational theory comprising a five-tier model of human needs; needs lower in the hierarchy must be satisfied before individuals can attend to higher needs. These needs are divided into deficiency (basic) needs (physiological, safety, love and belonging, and esteem) and growth needs (self-actualisation). Self-actualised people use their full potential.[19] Figure 2 shows Maslow's hierarchy of needs, as adapted to PCIC. Notably, it was difficult to sort dimensions by need categories when adapting Maslow's hierarchy to PCIC, as each dimension could include a mixture of deficiency and growth needs. For example, information provision could be a basic need (e.g. how to use a medication) or a growth need (e.g. detailed knowledge on IVF procedures to facilitate decision-making). The hierarchy indicates that participants focused on deficiency needs, as all nine dimensions are within the deficiency needs zone and did not reach self-actualisation. The IDI transcripts showed low expectations among participants, with few exceptions. Based on Maslow's hierarchy, this indicates that participants' deficiency needs were not covered, and they continued to struggle to receive infertility care. Thus, PCIC is expected to help Arab women experiencing infertility satisfy their deficiency needs and become motivated to achieve self-actualisation, thereby empowering them to participate in infertility care.

The current study found that the PCIC definition was shaped by the patient experience with infertility care. This finding indicates that this definition is dynamic and not static. The patient may provide different preferences if the concept was to be explored at different time points.

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To the best of our knowledge, this is the first study that showed a possible association between PCC and HSB. Generally, seeking infertility medical care has been shown to relate to prior experience with doctors.[20] In line with our findings, self-medication has been associated with some dimensions of PCC, including accessibility (especially lack of insurance coverage),[21 22] knowledge,[23] physical comfort,[23] and dissatisfaction with health care providers.[18] Huppelschoten and colleagues found no relation of PCIC with drop-out.[24] Our findings suggested the opposite, as PCIC was related to discontinuation of treatment and changing doctors or hospitals. Sansone and Sansone supported that inconvenient clinician factors promote doctor shopping.[25] Unlike other forms of HSB, using traditional and spiritual treatments was related to beliefs and preferences that favoured such treatments over conventional medicine, in line with previous studies.[20 26 27]

Limitations

Regarding limitations, our study was conducted in a single city. Collecting data from across Saudi Arabia, or more than one country in the Arab world, was infeasible due to a lack of funding. The current study highlighted the possible effect of PCIC on HSB; however, this association could not be confirmed due to the nature of qualitative research. Future quantitative studies are needed to confirm the association and, if proven, to consider HSB as an indicator of PCIC.

CONCLUSION

This study identified nine PCIC dimensions and items, which reflect the definition of PCIC and can guide efforts to improve the quality of Arab infertility care. Clear differences between the Arab and the European PCIC model were found. Our findings led us to conclude that women continue to exhibit unmet basic needs. We hope this study will prompt further research regarding PCIC in the Arab world and thereby provide more implications for improving the quality of infertility care and quality of life for women who experience infertility. This study created a list of PCIC dimensions and items but did not develop a tool to measure PCIC. Thus, further work is recommended to develop a validated tool for measuring PCIC from Arab patients' perspectives.

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Author Contributions
HHW, TATI, and SBI contributed to the study design. HHW and AJK collected the data. HHW, TATI, SBI, and AJK performed the data analysis and interpretation. HHW wrote the first draft of the article and all authors contributed to subsequent revisions.

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Patient consent for publication Not applicable.

Ethics approval The study proposal was reviewed and approved by the IRB of the Department of Medical Research and Studies, Directorate of Health Affairs, Ministry of Health, Jeddah, Saudi Arabia (number A00306); and the Human Research and Ethics Committee of Universiti Sains Malaysia (Number USM/JEPeM/15020056, Date 03/11/2015). The study was performed in accordance with the ethical standards as laid down in the 1964 Declaration of Helsinki and its later amendments. Informed consent was obtained from all participants. Respondents' privacy and confidentiality were assured.

Provenance and peer review: Not commissioned; externally peer reviewed.

Data availability statement: All data relevant to the study are included in the article or uploaded as supplementary information.

Supplementary data

Supplementary file 1: in-depth interview guide

Supplementary file 2: COREQ checklist for qualitative research

Supplementary file3: quotations showing participants' definitions of patient-centred infertility care (PCIC) and dominant events in each patient's experience

Figures:

Figure 1 Diagram shows the interaction between PCIC definition and patient experience, psychosocio-demographic features, and health seeking behaviour (rectangles)

Figure 2 Maslow's Hierarchy of Patient-centred infertility care (PCIC)

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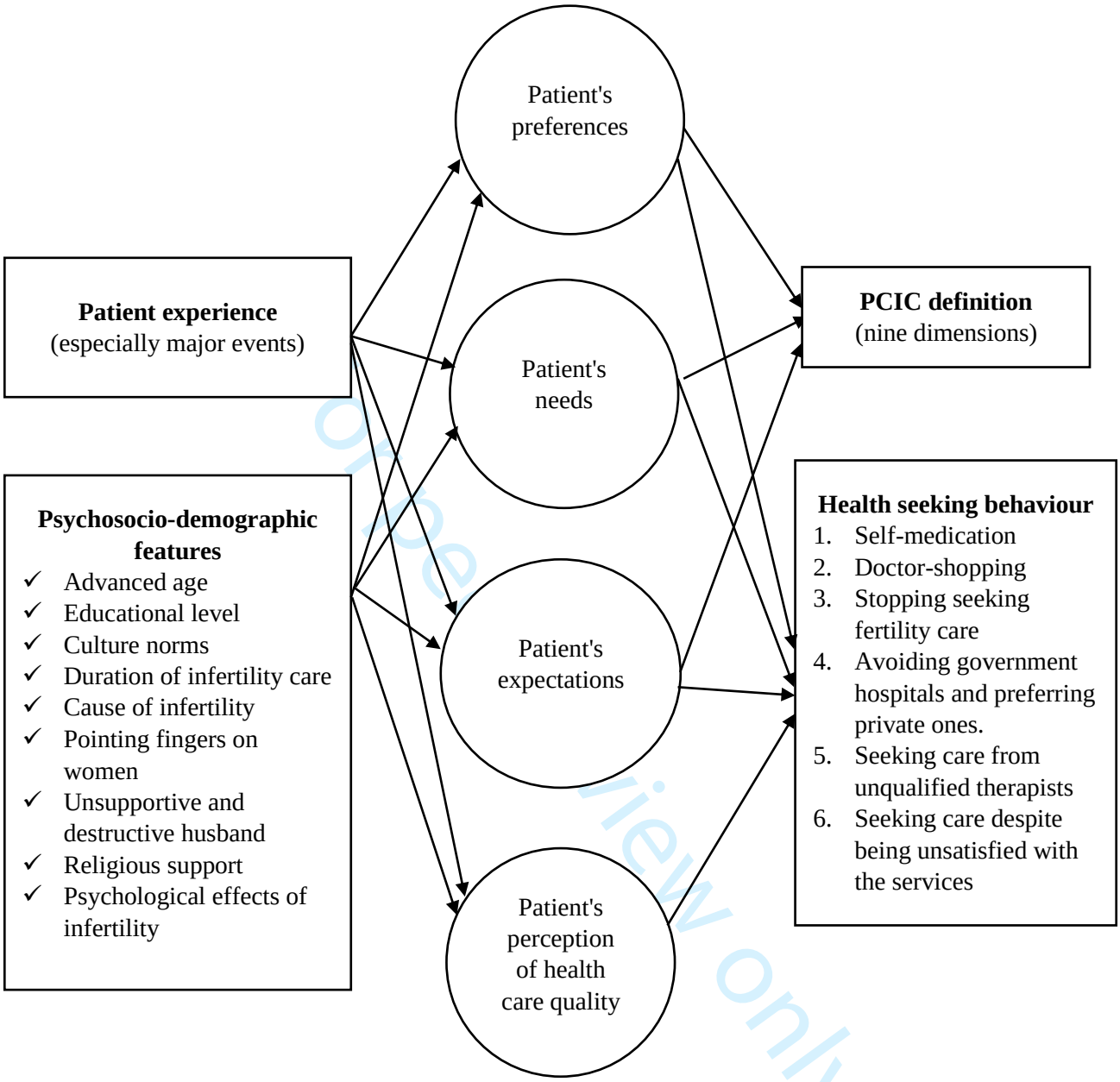

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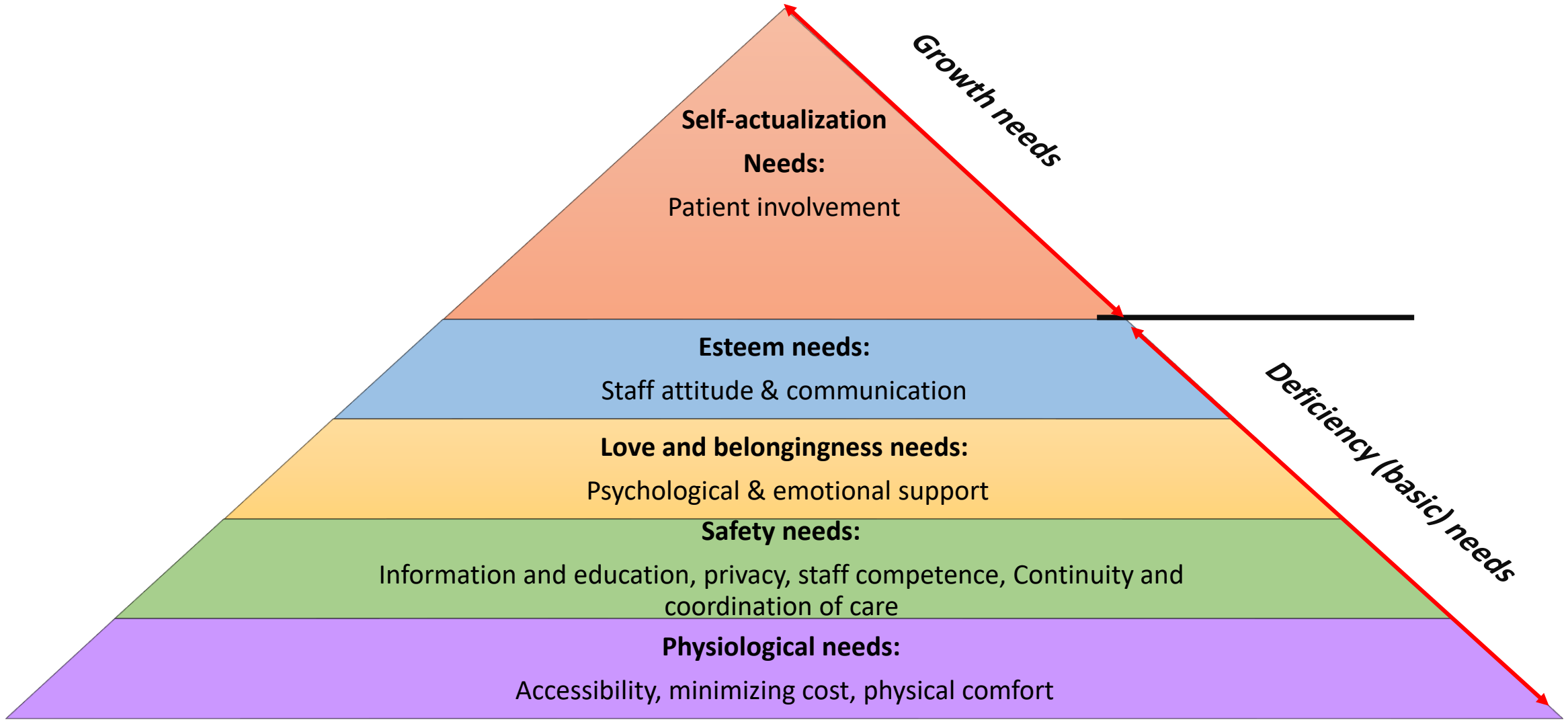
Growth needs
Self-actualization
Needs:
Patient involvement
Esteem needs:
Staff attitude & communication
Love and belongingness needs:
Psychological & emotional support
Safety needs:
Information and education, privacy, staff competence, Continuity and coordination of care
Physiological needs:
Accessibility, minimizing cost, physical comfort
Deficiency (basic) needs

1

Title Patient-centred infertility care among Arab women experiencing infertility: a qualitative study

Journal name: BMJ Open

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2

In-depth Interview Guide

Background Information

ID:	
Personal data	
Age (years):	Sex: ☐ Male ☐ Female
Education: ☐ Illiterate ☐ Primary ☐ Secondary ☐ Diploma ☐ Bachelor ☐ Master or higher	
Occupation	Address
Infertility-related data	
Duration of marriage (months):	Duration of infertility (months):
Duration of seeking fertility care (months):	No of pregnancies:
No. of live children:	Cause of infertility:
Are you (your wife) pregnant now? ☐ Yes ☐ No	
Where you had received fertility care; please write the name of clinic and hospital. If you sought more than one clinic, please mention them chronologically and specify the period in front of each. …… …… …… ……	

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3

In-depth Interview Guide (con'd)

Introduction Key Components	✓ Participant name and personal data ✓ Research information ✓ Signature of consent
Questions	1. What types of infertility medical care have you received? 2. What characteristics of infertility care, would you recommend be sustained and/or introduced? Please provide a justification for your response. 3. What are the things you have missed in your infertility care? 4. What do you think will work well in increasing utilization of infertility care? Please explain 5. How would you recommend for future infertility care? 6. If all what you have recommended above are made available, would you seek other non-medical source of care for infertility? Please justify 7. What are the elements of patient-centered fertility care from your point of view? Please elaborate N.B. -Probes should be used as needed.
Closing Key Components	✓ Is there anything more you would like to add? ✓ I'll be analyzing the information you and others gave me. I'll be happy to send you a copy of the result, if you are interested. ✓ Thank you for your time.

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دليل المقابلة المتعمقة

مكونات المقدمة الرئيسية	✓ البيانات الشخصية ✓ معلومات حول البحث ✓ التوقيع على الموافقة
الأسئلة	١. ماهي أنواع الرعاية الطبية لتأخر الحمل التي خضعت لها من قبل؟ ٢. ماهي مواصفات الرعاية الصحية لتأخر الحمل التي توصين أن نبقي عليها أو نستحدثها؟ أرجو تبرير جابتك ٣. ماهي الأشياء التي افتقدتها أثناء تلقيك الرعاية الطبية لتأخر الحمل؟ ٤. ماهي الأشياء التي تعتقدين أنها ستكون فعالة في زيادة الاستفادة من رعاية تأخر الحمل؟ أرجو الشرح ٥. كيف تنصحين للرعاية الطبية لتأخر الحمل في المستقبل؟ ٦. إذا تم توفير كل ما أوصيت به أعلاه, هل ستلجئين لوسائل أخرى غير طبية لعلاج تأخر الحمل؟ أرجو التبرير ٧. ماهي مكونات الرعاية المتمركزة حول المريض من وجهة نظرك؟ أرجو التفصيل ملاحظة: - ستستخدم التحقيقات حسب الحاجة
مكونات الخاتمة الرئيسية	✓ هل هناك أي شيء تودين إضافته؟ ✓ سأقوم بتحليل المعلومات التي أعطيتني أنت و غيرك من المشاركين. سأكون سعيدا لأرسل لك نسخة من النتيجة، إذا كانت تهمك. ✓ شكرا لك على وقتك

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COREQ (COnsolidated criteria for REporting Qualitative research) Checklist

A checklist of items that should be included in reports of qualitative research. You must report the page number in your manuscript where you consider each of the items listed in this checklist. If you have not included this information, either revise your manuscript accordingly before submitting or note N/A.

Topic	Item No.	Guide Questions/Description	Reported on Page No.
Domain 1: Research team and reflexivity			
Personal characteristics			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?	
Credentials	2	What were the researcher's credentials? E.g. PhD, MD	
Occupation	3	What was their occupation at the time of the study?	
Gender	4	Was the researcher male or female?	
Experience and training	5	What experience or training did the researcher have?	
Relationship with participants			
Relationship established	6	Was a relationship established prior to study commencement?	
Participant knowledge of the interviewer	7	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	
Interviewer characteristics	8	What characteristics were reported about the inter viewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	
Domain 2: Study design			
Theoretical framework			
Methodological orientation and Theory	9	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	
Participant selection			
Sampling	10	How were participants selected? e.g. purposive, convenience, consecutive, snowball	
Method of approach	11	How were participants approached? e.g. face-to-face, telephone, mail, email	
Sample size	12	How many participants were in the study?	
Non-participation	13	How many people refused to participate or dropped out? Reasons?	
Setting			
Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace	
Presence of non-participants	15	Was anyone else present besides the participants and researchers?	
Description of sample	16	What are the important characteristics of the sample? e.g. demographic data, date	
Data collection			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested?	
Repeat interviews	18	Were repeat inter views carried out? If yes, how many?	
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	
Field notes	20	Were field notes made during and/or after the inter view or focus group?	
Duration	21	What was the duration of the inter views or focus group?	
Data saturation	22	Was data saturation discussed?	
Transcripts returned	23	Were transcripts returned to participants for comment and/or	

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Topic	Item No.	Guide Questions/Description	Reported on Page No.
		correction?	
Domain 3: analysis and findings			
Data analysis			
Number of data coders	24	How many data coders coded the data?	
Description of the coding tree	25	Did authors provide a description of the coding tree?	
Derivation of themes	26	Were themes identified in advance or derived from the data?	
Software	27	What software, if applicable, was used to manage the data?	
Participant checking	28	Did participants provide feedback on the findings?	
Reporting			
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	
Data and findings consistent	30	Was there consistency between the data presented and the findings?	
Clarity of major themes	31	Were major themes clearly presented in the findings?	
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes?	

Developed from: Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357

Once you have completed this checklist, please save a copy and upload it as part of your submission. DO NOT include this checklist as part of the main manuscript document. It must be uploaded as a separate file.

Manuscript Title Patient-centred infertility care among Arab women experiencing infertility: a qualitative study

Journal: BMJ Open

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Panel: Quotations showing participants' definitions of patient-centred infertility care (PCIC) and dominant events in each patient's experience	
'we lacked health awareness. I may enter to do dental x-ray; they do not tell me you should cover your body with a special cover. So, if you don't know, you will not find guidance. Information and awareness raising are first. Awareness raising and stop putting everything on the woman'. **Participant 1: 30- 35 years age group, primary infertility, male factor** Doctors treated her as the cause for infertility and did not investigate her husband. As a result, she was exposed to unnecessary treatment for nine months, with no benefit. Finally, they performed a semen analysis and diagnosed male-factor infertility. The option of IVF was not discussed with her, and the doctor instead prescribed medication. She searched for a second opinion and knew the best option for their case was IVF.	*'Regarding infertility treatment, case study…means to study all aspects…Regarding diet, psychological comfort, the patient who does something which causes the problem...I mean, I should revise the patient's case, the routines in her life. There are fixed essentials in a patient's life that could be wrong and could be the cause behind her problem'.* **Participant 2: 35-39 years age group, secondary infertility, 3 daughters, endometriosis.** She had three daughters from her first marriage spontaneously. After her second marriage, she developed endometriosis, with recurrent cysts and adhesions, which caused pain and infertility. She was very upset by this new issue in her life, and how the modern medicine did not find the cause behind it. She lived in a city away from Jeddah, with an unsupportive husband who gave up on operations and follow-up. She had very poor mental health.
'I feel it should be the same as when I delivered for the second time. The doctor welcomed me warmly! She asked me what type of delivery I'd prefer to have—this should be your choice. I told her I wanted to deliver normally. She told me, I will give you a paper to sign, and I will do my best to deliver you normally. If there is even one percent risk for you or the baby, excuse me, I will shift you to caesarean. I mean, she explained everything for you! When she came to do anything, she explained it for me—I will do so and so for this purpose. Although I did not understand their language—it was in America—everything was by sign language. I mean, there was a big	*'It is clear from the words that it means when the doctor becomes interested in his patient, what the patient likes and prefers. As I mentioned, to treat the patient as a human, the way he is comfortable, without forcing him. To give him his due. For example, if there are two medicines with the same effect, I should prescribe what the patient is comfortable using. To deal with the patient in a humanitarian, not materialistic way. For example, when I gave birth to my daughter, I wanted to give the doctor who delivered her a gift, because she supported and helped me. People says it is her duty! But the doctor who knows his job makes people feel comfortable'.*

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difference in her attitude, from my first delivery. This is patient-centred care'. **Participant 3: 25- 39 years age group, secondary infertility, 2 sons, ovulatory cause** Complained of inadequate information, especially regarding medication, and the absence of collaboration in management planning. She needed to ask her physician about medication, but could not reach her, due to having no method for communication. She looked for a second opinion (her friend was a doctor), who gave her a plan that was different from her doctor's plan. She was confused and unsatisfied.	**Participant 4: 35- 39 years age group, secondary infertility, son & daughter, hyperprolactinemia** She did not like medication or hospital work-ups, and preferred natural remedies. She started complementary medicine, and when it failed, she sought medical care. She had irregular visits, then she stopped seeking care due to lack of appropriate appointments, very expensive treatment, and lack of support from her husband. Her husband blamed her for the infertility, although both of them had children from their first marriages, and refused semen analysis, so her doctor refused to treat her. One doctor told her she was the cause of the infertility, and another one told her after all that, you want to get pregnant (2 kids and 34 years old)!
'If we make treatments personalised, if we talk about the patients themselves... my doctor was treating me, and told me, "you are overweight, so you should drink a lot of water", talking about me personally', **Participant 5: 25- 29 years age group, primary infertility, ovulatory cause** She thought obesity was the cause of her infertility. She tried treating this in a public hospital, but discontinued because they dealt with her disease-wise, not as a person. She started obesity treatment on her own, for herself and her husband. She went to a doctor in a public hospital, despite the very poor environment and services, and the presence of trainees, only because that doctor personalised her treatment.	*'The doctors and the nurses themselves should be good. Also, the place, the hospital itself, prepares you. The cleanliness of the hospital…The devices should be advanced enough, some hospitals are really….that's all'.* **Participant 6: 20-24 years age group, primary infertility, unexplained infertility** She had a bad experience with materialistic doctors and no health benefits. She also had bad experiences with public hospitals that lacked facilities and were a poor environment. She shifted to a private hospital, although it was expensive. The cause of her infertility remained unknown until finally, she visited a doctor who recommended a scope for the first time. She was sad nobody told her about it before!

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'The first thing is to take care of patients and treat them. Treatment, for example. I mean, to care about treatment and medications, what is the patient's problem—from what? Yes, they should know what the patient's problem is and treat it'. **Participant 7: 40-45 years age group, secondary infertility, no living children, male factor** The cause was unknown, apart from her age. Then, her husband developed male factor infertility after one failed IVF. She followed up in both public and private hospitals. She used traditional medicine when doctors did not diagnose the cause of her infertility.	*'To study the case well from the start. To study the case seriously! Not only try, try haphazardly, and that's it. No! To study the case seriously! To consider the financial circumstances. To give it high priority, not only, "this what we have, do it"'.* **Participant 8: 40-45 years age group, secondary infertility, 2 living children, unexplained infertility** She had recurrent miscarriages after two births. Now, she is over 40. She received conflicting opinions from different doctors. Finally, after six miscarriages and getting older, she knew the best option in her case was to test the abortus for genetic disorders. However, because it was not done, she could try IVF with genetic testing for the embryos. She knew it would cost around 30,000 SR, which is out of her ability. So, she does not trust doctors and would habitually seek four different doctors' opinion before starting any treatment.
'Do you mean all of this could be centred on me? So, the patient should have interests, have awareness, have… right? Aha! to.. of course, you cannot control that, why? Because there will be overload, so doctors will not be able to cover it all. So, whatever I tell you, it will not be covered fully; therefore, whatever you do for me I will not see anything! Aha! It depends on the patient and complaint, you know? Apart from that, the most important thing is psychological preparation'. **Participant 9: 35-39 years age group, secondary infertility, 2 daughters, undiagnosed infertility (husband refused semen analysis)** Her husband is very unsupportive and destructive. She has had poor experiences with the female doctors and good experiences with male ones, regarding	*'The term means to make appointments booking easily available and to listen to me. Yes! And to listen to me, I mean to hear me well, and my interests, and so on. I mean the same thing—the discrimination. To avoid discrimination when dealing with patients'.* **Participant 10: 30-35 years age group, secondary infertility, daughter & son, ovulatory cause** She had secondary infertility after her first daughter, and was on ovulation induction for a long time. First, she went to doctors for that purpose. Then, because it is difficult to find appointment soon, and this caused missing the chance for following ovulation and intercourse timing, thereby delaying treatment, she started taking medication illegally and following ovulation in any polyclinic nearby. She had a lot of questions and was in a hurry to get pregnant, as she had marital instability and her social norms meant

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communication skills. She felt men are easier to understand.	she should have many children. Doctors gave up answering her questions. She had ovarian cysts and two operations.
'The most important thing is the behaviour of the doctor, also the receptionist, and the hospital as a whole. The nurses and all should serve the patient. I mean, some of them, their behaviour is as if you are coming to panhandle. As if they are not employed and receiving salaries! They should serve us and others. This is their job'. **Participant 11: 30-35 years age group, primary infertility, tubal factor?** She lived far away, but chose to come to Jeddah, because her friend had a positive experience. She started in government hospitals, then after long wait times and offensive behaviour from one doctor, she shifted to a private hospital, although it was very expensive.	*'First should be to pay attention to the patient's psychological status. To pay attention to the patient's feelings. I mean, do not destroy patients. For example, if there is no effective treatment! Or if the sperm is of no value! This sometimes destroys the patient'.* **Participant 12: 25-29 years age group, primary infertility, male factor** She had failed intrauterine insemination and IVF attempts. She discovered afterwards that her doctor did not disclose to them the male factor or low success rate. She planned to change to another doctor, but could not pay the cost. She contacted an unlicensed therapist through Instagram who claimed he had medicines for sperms count and quality. She was so happy with his way of communication and that he listened to her whole history that wanted to continue with him.
'I hope there is something like this. It is awesome! To not be purely materialistic. Actually, the cost should not be huge. The situation should not be purely materialistic. I mean, I have to pay for anything to be done for me! For example, for the psychologist, I need to pay a large sum of money! For each visit he sets with me, I will pay?! No'. **Participant 13: 40-45 years age group, primary infertility, tubal factor** She started medical treatment, but it failed. It was found that her fallopian tubes were blocked. IVF was recommended, with some procedures beforehand. She could not do it, due to cost. She complained of social pressure and blame. She did not understand doctors well because they spoke English.	*'The care, by all means, is patient-centred. There is a discussion between the doctor and patient. The doctor provides what he has, if the patient does not like something, the patient should say so. Yes. So, it depends on the patient. If the patient discusses matters with the doctor, they will find an answer. But if the doctor spontaneously asks the patient what do you want? No! Here, I will be in doubt—is this really a doctor'?* **Participant 14: 25-29 years age group, 1ry infertility, ovulatory cause** She had an ovarian cyst with pain and dyspareunia. She started with a doctor who treated her with medications that showed no benefits. She then changed to another doctor, who removed the cyst surgically. She went to a third doctor for infertility, who gave her a clear plan from the start (still ongoing).

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