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

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

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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'.*

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!

'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

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).