ORIGINAL ARTICLE

CHARACTERISTICS OF PEOPLE WITH INFERTILITY IN INDONESIA REFLECTED IN FERTIQOL SCORES

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ABSTRACT

This study aimed to assess the early psychometric condition of people with infertility in Indonesia using the Indonesian online Fertility Quality of Life (FertiQoL). The online FertiQoL was developed with the PT. Integra Inovasi Indonesia and aimed at women/men over 18 years of age who have problems with infertility, and have or have not undergone treatment and can be accessed on https://integra.web.id/fertiqol-int/ and is open to the public and is easily accessed via a personal computer/Smartphone. R project version 3.6.3 was used for data merging and statistical analyses, i.e. two sample t-test or ANOVA). There were 214 participants from all over Indonesia. There were three Sociodemographic factors that gave significant differences. The first was age on the Mind/Body, Social, Core FertiQoL and Total FertiQoL subscales; the second was education, on the Environment and Tolerability subscales; and the third was medical conditions on the Environment subscale. In group 4 there were participants who have undergone consultations, diagnostic tests, and infertility treatment. The results of the Indonesian version of the online FertiQoL showed that 32.72% of people with infertility experience mental disorders, namely depression (16.36%) and anxiety (16.36%).

Keywords: FertiQoL, infertility, Indonesia, quality of life, socio-demography variables.

INTRODUCTION

Primary infertility has an estimated prevalence of 10.2% in Indonesia's population of women aged 15-49 years. The largest community is the group of women aged 15-19 years. Infertility can happen due to early marriage, when there is no physical and psychological readiness to be married nor have the enthusiasm to get pregnant and have a baby.[1] Depression is closely linked to alternative stress, namely anxiety, which affects the release of cortisol, and its symptoms can be seen in approximately 37% of infertile women. Both emotions (depression and anxiety) are consistently prevalent in women who are infertile. This pattern often occurs in infertile couples, and more in women who have infertility than fertile women.[2]

Women who always fulfill the infertility criteria and who have some fertility problems are less satisfied in life and are often considered weaker than working women who have children. Conversely, research found there were no anxiety nor depression about the demand of motherhood for women having higher life satisfaction who live with infertility and did not feel there was a problem.[3] Dissatisfaction with being a mother may have quality-of-life (QoL) implications for women to experience stress related to marital life while partner attitudes also hinder the success of infertility treatment.[4] The most popular measuring tool to determine the QoL for people with infertility is the Fertility Quality of Life (FertiQoL), which is a reliable measurement to know the impact of fertility problems and their treatment on QoL.[5,6]

To our best knowledge, there are no data published on the general QoL of infertile people in Indonesia. This study aimed to assess early psychometric conditions of people with infertility in Indonesia using the FertiQoL online questionnaire.

METHODS

Project site and patient selection

This research was a cross-sectional study. Before beginning, study approval was obtained from the Medical and Health Research Ethics Committee of the Faculty of Medicine, Public Health and Nursing, Universitas Gadjah Mada with (Ref No: KE/FK/0476/EC/2019). Data collections were administered simultaneously. In the first stage before the online trial, each question item and answer choice was evaluated because the Likert scale that was already in the international FertiQoL questionnaire in Indonesian was confusing and respondents were unfamiliar with the choices. This adjustment was made to make it easier for participants to understand the questions and answer choices. The second stage was the development of an online FertiQoL questionnaire

by the IT and Software Team from PT. Integra Inovasi Indonesia. The third stage was to determine a scoring formula per dimension based on scoring guidelines and locking questions that must be answered. The fourth stage was to test the online scoring accuracy compared to the manual score; this trial-and-error stage was done several times. The fifth stage was to create a promotional poster that aims to recruit participants who match the criteria. This poster was distributed to the in-vitro fertilization (IVF) peer support group, namely the *Pejuang Tangguh Permata Hati* Group, IVF clubs, clinics that serve pregnancy programs and through other groups on social media. Two hundred and fourteen (n=214) online participants completed the FertiQoL questionnaires from August 2019 to May 2020 in all Indonesia districts. All participants who voluntarily and anonymously completed the survey were enrolled this study. The questionnaire from FertiQoL has been converted into a website and is open to the public via the https://integra.web.id/fertiqol-int/ website.

The FertiQoL tool
The FertiQoL tool is a self-reporting questionnaire specifically designed to evaluate QoL of infertile patients by the European Society for Human Reproduction and Embryology (ESHRE) experts. The FertiQoL tool comprises two main modules: the Core Module for FertiQoL and ten Items for FertiQoL Treatment. The 24 Core FertiQoL items are divided into four fields: the emotional and cognitive, the physical (mind/body), the relational, and the social. The dynamic environment assesses the effect on emotions such as sadness, resentment or infertility grievance. The mind/body part refers to the effect of infertility on physical health, cognition and behavior. In the field of relations and the social domain the impact of infertility on partnerships and social aspects are quantified, respectively (e.g., social inclusion, expectations, and support). The optional module consists of two fields used for environmental assessment and tolerance for the treatment of infertility. Items from these domains are presented randomly and rated on a scale of 0-4 in the questionnaire. The subscale FertiQoL and total values are calculated and converted to 100. Higher scores indicate better QoL. FertiQoL is available in 46 different languages, including Indonesian, on the FertiQoL website (https://www.fertiqol.org/).

Data analysis
R project version 3.6.3 was used for data merging and statistical analysis. Two sample t-tests or one-way variance analyses (ANOVA) tests were used for testing differences between the groups. The alpha was set to 0.05. A *p*-value of 0.05 was considered statistically significant. Before doing the comparison test, first the distribution of the data was checked. If all the variables tested were normally distributed, the comparison test was done using the ANOVA test. If at least one group of variables tested was not normally distributed, the comparison test was done using the Kruskal Wallis test[7].

RESULTS

Participants participating in this study by completing the FertiQoL were: women and men who were over 18 years of age; experiencing infertility problems; while participants who did not have a partner at the time of the study were not required to answer questions about marriages or partnerships marked with an asterisk. The optional module of FertiQoL care is relevant only for people who have used fertility medical services (which include medical consultations or interventions); additionally, the response period for the item is given according to current thoughts and feelings. All participants were domiciled in Indonesia and have Internet access. Participants who had undergone infertility examinations or treatments at government and private health facilities were 18.7% and 14.0%, respectively, the remaining 67.3% did not complete or had not undergone an infertility examination.

The group of participants that filled the most online FertiQoL data were between the ages of 30 and 40 outside Java or on the island of Java, with an average age of 33 years, most of whom were married couples. Female participants provided more data than male participants. Some of the possibilities for this pattern is that women mainly have infertility, and/or men experience difficulty to complain about their condition. Most of the education levels were Bachelor degree (55.1%). Generally, there were 34 people with higher levels of education from master to doctoral levels (15.9%). As many as 98 people (45.8%) at the time of the study had consulted a medical doctor, underwent diagnostic testing and started treatment, namely IVF, or other programs wanting other children and help to deal with infertility problems. Forty-two participants (19.4%) had not consulted a doctor, with 19.0% who live on the island of Java and 26.3% outside the island of Java (Table 1).

Based on the results of Table 2 above, the subdomain with a *p*-value < 0.05 means that at the 5% significance level, H_0 was rejected so that there was a significant difference/effect of age on the score in the dimensions of mind/body, Environment, Core FertiQoL and Total FertiQoL between age groups.

The conclusion from the above output was that the *p*-value > 0.05 means that at the 5% significance level, H_0 was accepted so that there was no significant difference between the scores in all domains for participants who were single and married (Table 3).

Table 1. Demographic characteristics of FertiQoL online samples

	Java Island (N=195)		Outside Java Island (N=19)	
	n	%	n	%
Age (y)				
≤ 30	62	31.8	5	26.3
31-40	111	56.9	13	68.4
> 40	22	11.3	1	5.3
Mean	32.58		33.51	
SD	6.68		6.63	
Relationship status				
Single	26	13.3	4	21.1
Married	169	86.7	15	78.9
Sex				
Male	11	5.6	1	5.3
Female	184	94.4	18	94.7
Educational level				
≤ High school	54	27.7	2	10.5
Bachelor	108	55.4	10	52.6
Master or higher	27	13.9	7	36.8
Other	6	2.8	0	0
Medical Condition				
Have not consulted a doctor	37	19.0	5	26.3
The consultation did not have a diagnostic test	30	15.4	4	21.1
Have consulted and have diagnostic tests	36	18.5	4	21.1
Have consulted, diagnostic tests and started treatment	92	47.2	6	31.6

Table 2. Comparison test of FertiQoL scores by age group

	≤ 30 year (N=67) (Mean ± SD)	31-40 year (N=124) (Mean ± SD)	> 40 year (N=23) (Mean ± SD)	P Value
Emotional	60.14 ± 18.43	59.77 ± 16.11	70.28 ± 19.97	0.42[a]
Mind/Body	57.83 ± 16.02	59.41 ± 16.44	69.72 ± 19.13	0.04[a]
Relational	77.23 ± 17.24	76.80 ± 13.74	79.17 ± 13.36	0.75[b]
Social	60.54 ± 19.18	63.79 ± 17.76	80.28 ± 17.43	0.003[b]
Environment	63.23 ± 14.78	61.12 ± 14.68	58.82 ± 12.18	0.59[b]
Tolerability	68.20 ± 20.12	63.14 ± 20.17	65.63 ± 17.97	0.28[b]
Core FertiQoL	62.58 ±14.28	64.94 ± 12.90	74.86 ± 15.17	0.006[a]
Treatment FertiQoL	65.22 ± 12.76	61.83 ± 12.48	62.14 ± 11.13	0.25[a]
Total FertiQoL	62.77 ± 12.88	64.12 ± 11.42	71.82 ± 13.88	0.03[a]

a ANOVA test

b Kruskal Wallis

Table 3. Comparison test of FertiQoL scores based on marital status

	Single (N=30) (Mean ± SD)	Married (N=184) (Mean ± SD)	P Value
Emotional	61.53 ± 19.47	60.51 ± 17.13	0.73[a]
Mind/Body	54.72 ±15. 92	60.30 ± 16.67	0.80[b]
Relational	4.17 ± NA	77.51 ± 13.77	0.09[a]
Social	67.92 ± 16.09	62.99 ± 19.20	0.18[a]
Environment	60.83 ± 10.24	61.74 ± 14.73	0.88[a]
Tolerability	65.63 ± 26.56	64.90 ± 19.66	0.70[a]
Core FertiQoL	60.98 ± 15.09	65.33 ± 13.61	0.41[b]
Treatment FertiQoL	62.75 ± 13.91	62.94 ± 12.46	0.12[b]
Total FertiQoL	60.10 ± 14.33	64.79 ± 11.88	0.54[b]

a Mann Whitney test

b t test

Table 4. Comparison test of FertiQoL scores based on gender and geographic area

Gender	Female (N=202) (Mean ± SD)	Male (N=12) (Mean ± SD)	P Value
Emotional	60.60 ± 17.58	61.45 ± 15.40	0.94[b]
Mind/Body	59.22 ± 16.62	64.58 ± 16.99	0.28[a]
Relational	77.23 ± 14.64	75.348 ± 16.80	0.81[b]
Social	63.98 ± 18.85	58.68 ± 18.76	0.18[b]
Environment	61.55 ± 14.70	63.54 ± 11.67	0.47[b]
Tolerability	65.04 ± 19.97	63.54 ± 21.62	0.72[b]
Core FertiQoL	64.70 ± 13.91	65.01 ± 13.89	0.94[a]
Treatment FertiQoL	62.88 ± 12.76	63.54 ± 8.42	0.86[b]
Total FertiQoL	64.11± 12.40	64.58 ± 11.51	0.90[a]
Geographic area	Java Island (N=195) (Mean ± SD)	Outside of Java Island (N=19) (Mean ± SD)	P Value
Emotional	60.64 ± 17.69	60.75 ± 15.04	0.89[b]
Mind/Body	59.78 ± 16.34	56.80 ± 19.70	0.22[a]
Relational	77.76 ± 13.76	70.31 ± 22.25	0.20[b]
Social	64.06 ± 18.77	59.86 ± 19.65	0.34[b]
Environment	61.85 ± 14.24	59.82 ± 17.87	0.71[b]
Tolerability	65.53 ± 19.76	58.04 ± 22.53	0.17[b]
Core FertiQoL	65.06 ± 13.83	61.22 ± 14.24	0.25[a]
Treatment FertiQoL	63.25 ± 12.48	59.11 ± 12.66	0.23[a]
Total FertiQoL	64.53 ± 12.26	60.08 ± 12.61	0.13[a]

[a] t test
[b] Mann Whitney test

The conclusion from the above output was that the p-value for all domains was > 0.05. This means that at the 5% significance level, H_0 was accepted so that there was no significant difference between the FertiQoL scores of male and female participants and that there was no significant difference between the FertiQoL scores for participants inside and outside Java. This result indicated that the geographical conditions did not affect the FertiQoL score in all sub-domains (Table 4).

Environment and Tolerability sub-domains have significant differences between education groups. From the output above, the p-value was 0.01 (F count = 3.718), which means at the 5% significance level, H_0 was rejected so that there was a difference in environmental scores between educational groups. Or it can be interpreted that there was an influence from the level of education on the respondent's environmental score. The tolerability subdomain from the above output obtained a p-value of 0.007, which means that at the 5% significance level, H_0 was rejected so that there was a difference in tolerability scores between educational groups. Or it can be interpreted that there was an influence from the level of education on the tolerability score (Table 5).

From the output above, only the Environment subdomain had a p-value of 0.0003 (F count = 6.643), which means, at the 5% significance level, H_0 was rejected so that there was a difference in environmental scores between groups of medical conditions. Or it can be interpreted that there was an effect of medical conditions on participants' environmental scores (Table 5).

The categorization of FertiQoL values in this study used cut-off points from the results of research conducted on Turkish women after previously completing sensitivity analysis to two different cut-off points. This study measured the validation for the level of QoL associated with stress, namely depression and anxiety, which are the core values of FertiQoL 58 and 51[8], as summarized in the following Table 5.

Based on the results of the online FertiQoL, 35.3% of women who had undergone IVF experienced depression and 17.7% experienced anxiety. In women with IVF among these participants, two people experienced severe depression and needed to receive professional treatment. Women who experience failure in fertility treatment and cannot repeat the IVF cycle due to age constraints and who had financial factors experienced this depression. Women with IVF experience feel a double burden of disease (both mental and physical) more than those with infertility who have not yet reached this stage because, in addition to the financial burden that must be sacrificed, it also contributes to their sociopsychological disorders. In the results of the online FertiQoL, 32.7% of people with infertility experienced mental disorders, namely depression and anxiety (Table 5). Infertility therefore has an effect on social aspects (social inclusion, hope, and support). In these cases, the patients feel confused between hope and despair, often experiencing social stigma and anxiety. This problem was is exacerbated by

their families' lack of understanding, low or no support from friends, and social pressure leading to social isolation. Often, it involves feelings of inferiority in front of people who have children as

well as embarrassment in uncomfortable social situations such as religious celebrations where having many children is praised and prized.

Table 5. Comparison test of FertiQoL scores based on education level and medical condition and cut-off values points classification.

Education level	High School (N=56) (Mean ± SD)	Bachelor (N=118) (Mean ± SD)	Master or higher (N=34) (Mean ± SD)	Other (N=6) (Mean ± SD)	P value
Emotional	62.13 ± 18.42	59.29 ± 17.83	64.22 ± 14.69	53.47± 11.91	0.22[b]
Mind/Body	59.45 ± 16.10	59.08 ± 16.20	61.76 ± 19.23	56.25 ± 18.02	0.76[b]
Relational	75.40 ± 14.99	77.58 ± 13.12	77.15 ± 20.01	80.56 ± 5.05	0.67[b]
Social	63.47 ± 17.52	63.84 ± 19.78	63.97 ± 19.13	61.11 ± 12.82	0.97[b]
Environment	55.37 ± 12.48	63.31 ± 14.37	64.72 ± 15.89	55.21 ± 8.59	0.01[a]
Tolerability	73.52 ± 18.06	62.68 ± 19.55	60.63 ± 21.66	76.56 ± 15.63	0.007[b]
Core FertiQoL	64.05 ± 14.08	64.53 ± 14.07	66.81 ± 13.87	62.85 ± 8.63	0.80[a]
Treatment FertiQoL	62.63 ± 11.54	62.96 ± 13.16	63.08 ± 12.05	63.75 ± 10.10	0.99[a]
Total FertiQoL	63.51 ± 12.65	64.04 ± 12.56	65.65 ± 11.94	63.25 ± 7.92	0.88[a]
Medical conditions	1 (N=42) (Mean ± SD)	2 (N=34) (Mean ± SD)	3 (N=40) (Mean ± SD)	4 (N=98) (Mean ± SD)	P Value
Emotional	62.30±16.79	62.74±18.74	60.00±17.26	59.48±17.46	0.72[a]
Mind/Body	57.44±16.40	61.52±15.76	61.56±14.26	58.89±17.99	0.60[a]
Relational	73.41±21.70	78.09±12.15	76.87±13.57	77.75±14.15	0.92[b]
Social	64.38±15.48	67.52±20.09	63.13±19.05	62.29±19.68	0.57[a]
Environment	50.89±12.25	56.61±13.98	60.04±13.74	65.39±14.08	0.0003[a]
Tolerability	66.07±28.13	66.81±18.91	67.15±20.26	63.34±19.06	0.70[b]
Core FertiQoL	62.46±13.47	67.20±13.69	65.39±13.30	64.56±14.37	0.51[a]
Treatment FertiQoL	56.96 ± 8.39	60.69±12.87	62.88±13.12	64.46±12.44	0.13[a]
Total FertiQoL	61.47±12.83	65.65±12.69	64.70±11.99	64.53±12.13	0.45[a]

Cut-off values points classification	Depression		Anxiety		Good		Total	
	n	%	n	%	n	%	n	%
Women with IVF	6	35.3	3	17.7	8	47.1	17	100
People with infertility	29	14.7	32	16.2	136	69.0	197	100
Total	35	16.4	35	16.4	144	67.3	214	100

Medical condition:
1 = Have not consulted a doctor; 2 = The consultation has not had a diagnostic test; 3 = Have consulted and have diagnostic tests; 4 = Have consulted, diagnostic tests and start treatment
a ANOVA Test
b Kruskal Wallis test

DISCUSSION

The general term 'stress' in physiology refers to the body's non-specific answer to a demand for a change, and every incentive that may trigger it is called a 'stressor.' Although it typically has a negative connotation in psychological terms, in physical science, stress is defined as how stress stimuli cause the physiological processes and biological tissues to respond to pressures including natural forces such as changes in atmospheric pressure or environmental conditions such heat and cold. From a positive standpoint, the focus can thus represent the body's ability to be trained to perform best or to achieve the resilience to withstand the evolutionary stress people continue to experience over the centuries.[5]

The problem of infertility has the potential to have negative effects on the QoL of infertile couples.[2,9]

Emotional stress is also a contributing factor to infertility problems,[10] and this is one of the reasons that couples drop out of infertility treatment early.[11] An international instrument that measures the effect of fertility on the QoL of women and men who experience fertility problems is already available. Fertility Quality of Life (FertiQoL) is a reliable measuring tool to see the impact of fertility disorders and its treatment on the QoL of people with infertility and to evaluate psychometric conditions early.[6] As far as the researchers' knowledge, there is still very limited research on measuring the psychometric conditions of people with infertility using the FertiQoL instrument in Indonesia.

The results of this study shown in Table 1, based on the 214 FertiQoL questionnaires that were completed online, indicated all data could be processed and analyzed. This was because in the

settings in the online system, the answers could only be sent when all the required questions and data had been filled except for participants who were single because there were several questions with a sign of stars that should not be answered in their case. The Indonesian version of the FertiQoL questionnaire is attached in the supplementary files.

This study was comparing FertiQoL scores between age groups less than or equal to 30 years, 31-40 years, and over 40 years (Table 2). There were significant differences in the domain mind/body, Social, Core FertiQoL, and the Total FertiQoL score. These data indicate that the higher the age, the better the score for the mind/body. Most of the women or men at this age have experienced infertility for a long time so that they are wiser and can adapt to the problem of infertility. Infertility does not become a disturbance in daily activities; the concentration of their mind is not disturbed due to infertility. The couples keep living life together and accept the existing conditions. The same occurs in the social domain, where women/men at the age of less than 30 have a lower social value compared to those above the age level. At this age, they still feel that their family does not understand, lack support from friends, feel isolated, become embarrassed when encountering uncomfortable questions about children during festive days such as holidays or other social gatherings, and feel they cannot overcome infertility problems.

But as they get older, social pressure can slowly be overcome, and they can reach out for the support of family and friends that is needed. Realizing that infertility is not a disgrace that must be covered up, and occurs not because of their will but is beyond their control. Accordingly, the totals FertiQoL in the age groups were significantly different. These results are also in line with studies conducted on women in Iran, where older women had higher mean scores on the Mind/Body, Emotional and Social subscales than younger women.[13]

For the marriage factor (Table 3), there was no difference in the FertiQoL score between those who are married or not. This result means that marital status had no effect on the sociopsychological conditions of people with infertility in this study. In the analysis of the FertiQoL score based on Gender (Table 4), there was no significant difference between male and female participants. This result may imply that infertility is not only a burden on women but also a burden on men. One of the FertiQoL answers from the male participant stated that he was married to a woman who was born without a womb, so he did not demand to have children biologically within the marriage of the woman he chose. However, what becomes a burden is not from the couple but is pressure from outside when people always ask questions and force them to immediately have/do a pregnancy program even though they do not understand the problems this couple is actually experiencing. Accordingly, based on the results in this study, infertility is also a burden for both women and men.

This result is different from research conducted in Taiwan and Japan where women experience more stress, anxiety and depression due to infertility than men characterized by a higher FertiQoL score.[12,14] Research conducted by Galundia with 60 infertile male and female couples enrolled in the Udaipur City infertility clinic, which studied the effects of Gender on anxiety and depression using the Beck Depression inventory tool, revealed that infertile women have high anxiety and depression and infertile men have low pressure and depression. The study showed that women suffer more profound emotional distress than men in married couples with primary infertility.[15]

Research in Israel has shown that fertility problems are worse for women than for men and more adverse for women because of infertility. The unique emotional response shown by shyness was a strong result in the experience of infertility.[16]

Based on geographic factor grouping, namely living on the island of Java and outside the island of Java, there is no significant difference in FertiQoL scores (Table 4). This result means that the geographical factors have no effect on psychometric conditions and are not a psychological burden for them. But the analysis may reveal more of a financial burden for people with infertility outside the island of Java. Because the majority of FertiQoL data are participants who live on the island of Java, the answers of participants outside Java are not sufficient to see the difference between the two.

In the comparison test scores between education groups (Table 5), the results of statistical analysis show that the two domains that have a significant effect on the education group are environment and tolerability. This result means that the higher the level of knowledge, the more understanding of interactions with medical staff related to information on the quality of care, the quality of surgery and medical care, whether the fertility care staff understands the needs of people with infertility, whether the quality of service meets their emotional needs and the desired medical services are available. Participants who have experienced medical care up to the pregnancy program with IVF are on average highly educated and already understand whether the infertility services they have experienced are adequate. Compared to participants with high school education, they have not experienced the complexity of infertility services because they have only come to consultations and have not started treatment.

These results are also in line with differences in

the FertiQoL scores of the groups based on medical conditions (Table 5). The domain that has a significant difference in the environment, as explained above in medical condition number 4, namely that the participants have had consultations, diagnostic examinations, and started treatment. Most of them are undergoing treatment in infertility clinics or other tertiary health services. It is ensured that at this health facility, good interactions with medical staff and the needs they want are available because it has become a sub-specialty of the health facility. It is different when in medical condition number 2, which is just having a consultation but not having a diagnostic examination, has no experience when undergoing therapy at an infertility clinic because it is only limited to consulting doctors, midwives, or other health facilities besides the infertility clinic and has a lower level of satisfaction with services than with participants in the medical state 4. Having knowledge concerning people with infertility will change the attitudes of service providers toward approaches required by effective patient-centered care.

The value of each of the scores is between 0 – 100, where the higher the number indicates a good QoL. Since the FertiQoL was designed to identify psychopathology, there has not been a defined cut-off point for the score used to identify who needs more attention for counseling.[12] Based on the cut-off points, it was analyzed that 32.7% of people with infertility experienced mental disorders, depression, and anxiety (Table 5) and for satisfaction with their QoL, 92.1% answered mediocre to very dissatisfied, while those who expressed very little satisfaction was only 7.0%. These percentages reflect that the problem of infertility is very influential on satisfaction with their QoL and how they experience an immaterial burden that significantly impacts on their health condition.

In this study, the subscale with the lowest average value was the mind/body domain, with 59.52 (data not shown in the tables), and the highest was the relational subscale, with 77.12. The results of the FertiQoL generally describe the conditions felt by most people with infertility in Indonesia which have an impact on their physical health such as causing fatigue, pain, cognitive disorders such as low concentration, which have an effect on behavior, namely disrupting daily activities. Fatigue can be a result of having to undergo medical therapy or an IVF program that requires regular visits to the hospital, with long waiting times for queues, and participants who are far away from health facilities, of course, who struggle physically, mentally, and financially. For participants who are single but have experienced fertility problems for a long time, such as cases of endometriosis, they experience tremendous menstrual pain every month and sometimes their condition interferes with productive time and becomes a psychological burden, and this fear always appears before or during menstruation. High numbers on the relational score indicate that currently, the problem of infertility for some participants in Indonesia has not become a big problem for couples. Husband and wife relationships can still be well-conditioned, and even most couples, especially those who both experience (husband and wife) fertility problems can strengthen the relationship of husband and wife and assure each other that they can get through this problem together.

The results showed complex experiences for female participants. Three main themes were identified: infertility clinic services were not all in line with personal expectations while positively reflecting cultural and social standards. The connection between expressing the experiences of women cannot be separated into different fields. Liminality and infertility describe the experiences of women during and after the process. A patient-centered model for the treatment of infertility is required. Some women in the study were lost to follow-up during the transition despite experiencing failure in treatment or success. Conceptual development should include a relational understanding of the patient's experience to ensure realistic, relevant patient, clinical personnel, and the system are patient-focused infertility care. Psychosocial skills are recognized as a critical competence for fertility nurses in clinical practice. The relational conceptualization of the experience of the patients living with infertility provides additional information on the development of personnel and improves practical knowledge and skills.

Study limitations

This study's main limitation is that its design does not consist of comparing the psychiatric level of infertile people receiving treatment to those who do not, thus making clear sense of the challenges in receiving infertility treatment. However, there was a strong relationship between FertiQoL score and socio-demographic factors such as age, education, and health. Therefore, our results can be used in future studies as control scores for further comparisons. The relatively large and controlled sample size is another strength of this study. This study also contributes to the literature as one of the rare studies that assessed infertile people's psychometric characteristics. The internal consistency of FertiQoL's online version in Indonesian reached sufficient levels in the current research for further studies.

CONCLUSIONS

The results of the Indonesian version of the online FertiQoL showed that 32.7% of people with infertility experience mental disorders, namely depression as much as 16.7% and anxiety as much as 16.4%. FertiQoL appropriate can be used for guidance for psychology counseling.

Abbreviations

ANOVA: Analysis of variance; ASRM: American Society of Reproductive Medicine ; ESHRE: European Society for Human Reproduction & Embryology; FertiQoL: Fertility Quality of Life; IT: Information Technology; IVF: In vitro fertilization; MHREC: Medical and Health Research Ethics Committee; WHO: World Health Organization.

Ethics Approval and Consent to Participate

Ethics Committee Approval: Medical and Health Research Ethics Committee (MHREC) Faculty of Medicine, Public Health and Nursing Universitas Gadjah Mada's approval was obtained at the beginning of this study from May 2019 to May 2020 (Ref No: KE/FK/0476/EC/2019). All patients gave online informed consent at the first page FertiQoL online questionnaire and approved of the protocol before going to the next page and data collection.

Competing Interest

The author declares that there are no significant competing financial, professional, or personal interests that might have affected the performance or presentation of the work described in this manuscript.

Availability of Data and Materials

The data from online participants completed the FertiQoL questionnaires from August 2019 to May 2020 in all Indonesia districts. All participants who voluntarily and anonymously completed the survey were enrolled this study. The questionnaire from FertiQoL has been converted into a website and is open to the public via the https://integra.web.id/fertiqol-int/ website. Also, the reader may contact the corresponding author for further information.

Authors' Contribution

FD, MH,MA and DAP participated in developing the protocol, design and analytical framework for the study, FD participated testing research instruments, collecting data, analyzing data, and contributing to the writing and analyzing manuscripts. MH contributed to the up dated literature review and correction of the manuscript. MA and DAP participated in the design study and read the final manuscript, final data analyses, and contributed to the manuscript and writing. All authors then discussed the results and contributed to the creation of the manuscript. MH approved the final manuscript and all other authors have read and approved this manuscript.

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