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Development of an infertility perception scale for women (IPS-W)

Miok Kim¹ and Minkyung Ban^{2*}

Abstract

Purpose The purpose of this study was to develop an Infertility Perception Scale for Women (IPS-W).

Methods Initial items were based on an extensive literature review and in-depth interviews with five infertile women and fifteen women not diagnosed with infertility. Forty-one items were derived from a pilot survey. Data were collected from 203 women who had experienced intrauterine insemination (IUI) and in-vitro fertilization (IVF) more than once. The data were analyzed to verify the reliability and validity of the scale.

Results Four factors containing 21 items were extracted from the exploratory factor analysis (EFA) to verify the construct validity. The four factors of infertility perception scale were perceived feelings, personal stigma, social stigma, and acceptance. These factors explained 59.3% of the total variance. The confirmatory factor analysis (CFA) confirmed a four-factor structure of the 21-item IPS-W. All fit indices were satisfactory ($\chi^2/df \le 3$, RMSEA < 0.08). These items were verified through convergent, discriminant, known group validity, concurrent validity testing. The internal consistency reliability was acceptable (Cronbach's $\alpha = 0.90$).

Conclusion The scale reflects the perception of infertility within the cultural context of Korea. The findings can help nurses provide support that is appropriate for individual circumstances by examining how women experiencing infertility perceive infertility.

Keywords Infertility, female, Perception, Social stigma, Factor analysis, statistical

Introduction

Infertility, defined as the failure to achieve pregnancy within one year of regular unprotected sexual intercourse for couples of reproductive age, is perceived in the socio-cultural context of Korea as an impediment to an essential social rite of passage and a health problem that threatens family continuity [1]. In fact, Koreans struggling with infertility believe that giving birth to a child is

a prerequisite for a stable marital relationship and that having children allows the development of family relationships [2].

Infertility is perceived negatively due to the uncertainty, loss of control, and stressful situations [3] it causes, having a negative impact on quality of life [4]. Accordingly, decisions about treatment procedures should be made by each individual and as a couple after exploring various options and with an appropriate social support system. However, individuals with infertility often decide on infertility treatment without an appropriate decision-making process, due to the fear of experiencing social prejudice and negative perceptions when revealing infertility problems [5].

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The psychological difficulties faced by individuals with infertility are partly caused by negative social perceptions [5, 6]. Approximately half of all infertile couples tend to hide their infertility problem out of fear of social stigma [7]. Such stigmatizing views of infertility create a vicious cycle leading infertile individuals to have a negative perception of their problem, avoid or prematurely discontinue infertility treatment, and feel isolated from society [5].

Harzif, Santawi, and Wijaya [8] compared differences in perceptions towards infertility treatment between urban and rural areas by examining the level of knowledge on the risk factors for infertility, attitudes towards infertility, the social impact of infertility, and other options for infertile couples. However, as yet, the perceptions of the individuals receiving infertility treatment have not been specifically measured [9]. Despite the limited tools available for measuring infertility perceptions, some studies have assessed the stigmatizing characteristics of infertility; however, in most cases, the term "infertility" does not appear in the generic tools for measuring stigma [7, 10, 11]. Taebe et al. [5] developed the female infertility stigma instrument (ISI-F) based on the premise that infertility represents one of the biggest challenges in female reproductive and sexual health in most societies. However, the development of ISI-F relied on females attempting natural pregnancy, including ovulation induction. Consequently, while it shares some of the stigmatizing characteristics of infertile individuals, this tool may not adequately reflect the psycho-emotional difficulties of individuals receiving infertility treatments. The Infertility Stigma Scale (ISS) developed by Fu et al. [12] is designed to measure the perceived self-stigmas that a female receiving infertility treatment places on herself. However, the scale only encompasses the stigmatizing characteristics of infertility, therefore it does not allow for the assessement of the general perception that females undergoing infertility treatment have about their infertility, especially in a Korean context. The concept of stigma refers to a psychological attitude linked to a series of negative outcomes [12]. In contrast, perception refers to the process of recognizing and interpreting the nature and meaning of all types of stimuli and may vary depending on how individuals interpret the situation and the society they live in. Perception can be used to explore problems and make decisions on what should be changed and the strategy ahead [13]. Self-perceived stigma acts as a stress factor that leads to negative social stigma about infertility and interferes with life adaptation [14]; hence, it is all the more important to improve the perceptions of infertility.

Therefore, this study aims to develop a sensitive tool to measure how women who experience infertility treatment perceive their infertility, positioning them as active agents in coping with infertility. The goal is to assess their personal perceptions of infertility and facilitate a positive shift in those perceptions.

Methods

The development and validation of the infertility perception scale was performed in accordance with the method proposed by Devellis [15]. This study adheres to the Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) guidelines.

Development of the infertility perception scale Development of preliminary items

To identify the components of infertility perception, previous literature published in RISS, PUBMED, EMBASE, and NDSL were searched for relevant studies and existing tools in English or Korean. Only studies with full-text availability were included. The search keywords included "infertility," "fertility," "infertile women," "infertility for women," "infertility experiences," "experiences of infertility," "assisted reproductive technology," "intrauterine insemination," "in vitro fertilization," "perception," and "awareness." Among articles from PubMed, EMBase, and RISS, a total 42 articles were selected and reviewed, excluding duplicate articles (n=102), studies with no women subjects (n=48), studies not relevant to perception (n=205), systematic reviews (n=6), and case studies (n=21).

In-depth interviews were then conducted to confirm the initially identified items of infertility perception. The interviews were conducted separately for women who had not experienced infertility and women who were receiving infertility treatment to avoid the possible influence of social perception on the perception of infertility among the women under treatment [16]. Moreover, the emotional ups and downs experienced by individuals receiving infertility treatment may vary significantly depending on the number of follicles, the number and quality of the collected eggs, the need to undergo repetitive infertility treatments, and added negative emotions from previous failed treatments.

The women without experience of infertility were married women aged 20–69 years (three women per age group) selected by purposive sampling with consideration of their education level, economic status, and type of residence. The interviews, which lasted between 20 and 40 min, were conducted between April 7 and April 20, 2020.

Subsequently, interviews were conducted on six women undergoing IVF procedures to identify the central concept of infertility perception. Announcements were posted inside treatment centers to recruit potential participants. The interviews, which lasted between 50 and 70 min, were conducted between May 10 and May 18, 2020.

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The central question in the interviews was "How do you feel about infertility?" The supplementary question for women not diagnosed with infertility was "What did you think when you found out someone who was diagnosed with infertility or has experienced receiving infertility treatment?" The supplementary question for women receiving infertility treatment was "What feelings or thoughts did you have as you were diagnosed with infertility and undergoing infertility treatment?" The in-depth interviews were recorded with the consent of the participants, transcribed immediately, and analyzed according to the content analysis procedure proposed by Krippendorff [17].

After defining the conceptual framework through content analysis based on literature review and in-depth interviews, a total of 103 items were derived. Subsequently, duplicate items and those with unclear content were deleted, revised, or supplemented through a meeting with an expert with infertility nursing and research experience. As a result, a total of 66 preliminary items were derived, including 29, 18, and 19 items in personal, relational, and social dimensions, respectively.

To avoid central bias, during the instrument development process, the 4-point scale proposed by Lynn [18] was used to grade each item based on the level of agreement (1: "Strongly disagree" to 4: "Strongly agree"). The items in sections 1, 2, and 3 of the scale are reversescored, so that a higher total score indicates a more positive perception of infertility.

Content validity testing

In this study, content validity was tested twice by calculating the content validity index (CVI) based on expert opinion. The appropriateness of each item was assessed using a 4-point Likert scale (4: "Highly relevant"; 3: "Quite relevant"; 2: "Somewhat relevant"; and 1: "Not relevant"). Items with an Item-Content Validity Index (I-CVI)≥0.78 were selected. The first content validity testing was conducted in September 2020 by a 10-member expert panel [18].

The second content validity testing was conducted by five members from the first 10-member expert panel. Items with I-CVI≥0.78 were selected, leading to a total of 41 preliminary items.

Pilot study

A pilot study was conducted with 20 women living in city B who had been diagnosed with infertility and received at least one round of assisted reproductive therapy to assess the level of understanding about the instrument and the time required to complete the questionnaire. The number of participants was based on the sample size of 20–40 participants for pilot studies proposed by Devellis [15]. Item appropriateness was assessed through questions

such as "Are there any items that are difficult to understand?", "Are there any items with ambiguous expressions?", and "Are there any items that you believe lack relevance to the perception of infertility?"

Instrument evaluation

The instrument was assessed through item analysis, exploratory factor analysis (EFA), confirmatory factor analysis (CFA), convergent validity, discriminant validity, criterion validity, and reliability testing.

The subjects were married women aged 20 and above diagnosed with infertility; had received at least one round of IUI or IVF; currently receiving infertility treatment; understood the study's purpose; and signed an informed consent. Those who had difficulties in understanding and responding to the self-reported questionnaire; had problems with cognitive comprehension; or had other physical disorders in addition to infertility were excluded. Based on the criteria that a sample size more than 200 or approximately five times the number of items would be appropriate for factor analysis [15, 19] and considering a dropout rate of 10%, a total of 212 subjects were recruited.

Data was collected from eligible, voluntary participants from two hospitals between November 30, 2020 and February 5, 2021. In our study, a high valid response rate of 94.9% (203 valid responses out of 214 recruited participants) was achieved. This was primarily attributed to the structured approach in participant recruitment and data collection. Participants were initially approached by a researcher or trained assistant at the infertility treatment hospital, who provided a detailed explanation of the study's purpose, the voluntary nature of participation, and assurances of confidentiality. Only those who expressed voluntary willingness to participate were provided with a QR code to access an online survey, which took approximately 15 to 20 min to complete. Conducting the survey during patients' waiting times further facilitated participation. These factors collectively ensured that participants felt informed and comfortable in participating in the study.

For the concurrent validity, ISS developed by Fu et al. [12] was used. After obtaining permission, ISS was translated into Korean and was reviewed. Subsequently, the translated version was translated back into the original language and compared with the original items. The final version consisted of 27 items in Korean. The self-reported instrument consisted of four domains (self-devaluation, social withdrawal, public stigma, and family stigma) in 5-point scale (1: "Do not agree at all" to 5: "Strongly agree"). At the time of development, the reliability of the scale was indicated by Cronbach's alpha=0.94. Cronbach's alpha was 0.86, 0.77, 0.92, and 0.84 for self-devaluation, social withdrawal, public stigma, and

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family stigma, respectively. In this study, the reliability of the scale was indicated by Cronbach's alpha=0.97. Cronbach's alpha was 0.94, 0.86, 0.95, and 0.91 for self-devaluation, social withdrawal, public stigma, and family stigma, respectively.

Based on the evidence that a stigmatizing perception of infertility is associated with greater experience of negative emotions such as depression and anxiety [20], the Korean version of the Center for Epidemiologic Studies Depression Scale-Revised (K-CESD-R) [21] was used for known-group validity. The scale measures the severity of depressive symptoms according to four levels based on the frequency of the symptoms experienced during the past week. Each item receives 0 point for occurring never or rarely (during less than 1 day), 1 point for occurring some or a little of the time (1–2 days), 2 points for

Table 1 General characteristics of the subjects (N=203)

Characteristics	Categories	n (%)	Mean ± SD
Age (years)	20-29	13 (6.4)	37.0 ± 4.6
	30-39	122 (60.1)	
	40-49	66 (32.5)	
	≥50	2 (1.0)	
Job	Yes	149 (73.4)	
	No	54 (26.6)	
Infertile factor	Female factor	36 (17.7)	
	Male factor	13 (6.4)	
	Mixed factor	38 (18.7)	
	Unexplained	116 (57.2)	
Child	Yes	33 (16.3)	
	No	170 (83.7)	
Religion	Yes	86 (42.4)	
	No	117 (57.6)	
Current treatment	Intrauterine insemination	87 (42.9)	
	In vitro fertilization	116 (57.1)	
Miscarriage experience after	Yes	39 (19.2)	
fertility treatment	No	164 (80.8)	
Treatment cost affordability	Hardly affordable	32 (15.8)	
	Reasonably affordable	64 (31.5)	
	Easily affordable	107 (52.7)	
Beneficiary of govern- ment subsidy for	Yes	161 (79.3)	
current infertility treatments	No	42 (20.7)	
Experience of counseling for infertility	Yes	23 (11.3)	
,	No	180 (88.7)	
Spouse' support for infertility treatments	Active	12 (5.9)	
,	Neutral	52 (25.6)	
	Passive	139 (68.5)	

occurring occasionally or a moderate amount of time (3–4 days), and 3 points for occurring most or all of the time (5–7 days). The total scores for all the items of 0–15, 16–24, and 25–60 points were defined as normal, probable depression, and definite depression, respectively. According to Cho & Kim [22], the reliability of the scale was indicated by Cronbach's alpha=0.90 in the normal group (N=540), 0.93 in the clinical patient group (N=164), and 0.89 in the major depression group (N=46). In this study, the reliability of the scale was indicated by Cronbach's alpha=0.94.

Collected data were analyzed using SPSS version 25.0 program (IBM Corp., Armonk, NY, USA). The general and infertility-related characteristics of the subjects were analyzed by descriptive statistics using the frequency, percentage, mean, and standard deviation (SD). Item analysis was performed using mean, SD, skewness, and kurtosis. Moreover, item-total correlation analysis was performed, and items with an item-total correlation coefficient inferior to 0.30 were reviewed and deleted [23]. The construct validity was tested by EFA and the appropriateness of factor analysis was identified using the Kaiser-Meyer-Olkin (KMO) test and Bartlett's test of sphericity. Furthermore, principal component analysis was used for factor extraction, while varimax rotation was used for factor rotation. For determination of the number of factors, eigenvalue≥1, factor loading≥0.50, commonality≥0.40, and scree plot were considered [24].

The concurrent validity was tested using the Pearson's correlation between the developed instrument and ISS [12], while the known-groups validity was tested using K-CESD-R [26]. Meanwhile, the differences in the infertility perception scores among the normal, probable depression, and definite depression groups were analyzed using one-way ANOVA, while a post-hoc test was performed using Scheffe's test. Cronbach's alpha was calculated to test the reliability.

Results

General characteristics

The subjects' age averaged 37.03 ± 4.56 . The most response to cause of infertility was "unexplained" (57.1%). Most subjects (83.7%) had no children. The current treatments were IVF (57.1%) and IUI (42.9%). The 31.5% considered the treatment as moderately affordable, 15.8% viewed it as hardly affordable. The 11.3% had experience counseling for infertility. The 68.5% answered that their spousal support to infertility treatment was passive (Table 1).

Item analysis

Analysis of the items in the scale showed that the mean value was 1.27-3.00 and the SD was 0.48-0.97. The absolute skew and kurtosis values were 0.03-1.93 and

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0.07-4.32, respectively, satisfying the criteria of an absolute skew value ≤ 2.0 and absolute kurtosis value ≤ 7.0 [25]. Accordingly, since multivariate normality was confirmed, all items were used in the analysis. The item-total correlation coefficient was 0.04-0.77, with 12 out of 41 items (items #6, 8, 9, 15, 22, 25, 28, 33, 36, 37, 38, and 39) showing an item-total correlation coefficient ≤ 0.30 . Since these items were assessed as offering little contribution to the scale, they were deleted, leaving remaining items in the scale.

Validity testing

Construct validity testing

A KMO value of 0.91 for 29 items and a Bartlett's test of sphericity χ^2 value of 3137.40 (p<.001) wear measured, confirming that the data were appropriate for factor analysis. After the first EFA, two items that were double-loaded on two factors (items #30 and 31) were deleted. After the second EFA on the remaining 27 items, three items that were double-loaded on two factors (items #12, 29, and 35) and three items with factor loading<0.50

(items #1, 23, and 34) were deleted. Subsequently, the third EFA was performed using 21 items. The results showed a KMO value of 0.89 and a Bartlett's test of sphericity χ^2 value of 1997.07 (p<.001). Moreover, the commonality was 0.40–0.81, factor loading was 0.51–0.89, and there were four factors with eigenvalue>1, which had a cumulative explanatory power of 59.3% (Table 2).

Four factors extracted according to infertility perception explained 59.3% of the total variance. In social science, an explanation of 40–60% of the variance for multifactor patterns is considered to be sufficient [26]. Factor-1 was named "perceived feelings," consisting of six items explaining 34.6% of the total variance. Factor-2 was named "personal stigma," consisting of eight items explaining 12.0% of the total variance. Factor-3 was named "social stigma," consisting of three items explaining 6.6% of the total variance. Factor-4 was named "acceptance," consisting of four items explaining 6.1% of the total variance.

According to the results of the exploratory factor analysis, the 21-item IPS-W with 4 factors

Table 2 Exploratory factor analysis (N = 203)

	No.	. ItemFactor loading						
				F1	F2	F3	F4	Commu-nalities
Perceived	5	I feel a sense of loss due to not being able to have a child		0.89	0.11	0.06	0.06	0.81
feelings	3	I am feeling anxious at the thought that I may never have a child		0.86	0.14	0.07	0.07	0.77
	2	Inability to have a child means no hope		0.85	0.16	0.12	0.17	0.78
	4	Infertility itself is depressing		0.78	0.22	0.14	0.04	0.68
	16	Inability to have a child is something to be sad about		0.74	0.19	0.21	-0.07	0.64
	13	A person who bears the cause of infertility feels a sense of guilt		0.62	0.35	0.30	-0.06	0.60
Personal stigma	11	Infertility is an outcome of past behavior		0.13	0.72	-0.04	0.06	0.53
	18	A person who cannot have a child is a failure in life		0.21	0.69	0.18	0.34	0.66
	19	Infertility is shameful and something to hide		0.04	0.68	0.28	0.15	0.56
	10	Inability to have a child is usually a woman's problem		0.10	0.67	0.13	-0.01	0.47
	27	Anyone who cannot get pregnant does not have a healthy body		0.18	0.66	0.17	0.19	0.53
20		Infertility comes from a lack of effort		0.09	0.66	0.09	0.11	0.46
	14	Inability to have a child is proof of loss of femininity		0.35	0.58	0.16	0.10	0.49
	24	Infertility is a personal problem for those who bear the cause of infertility		0.18	0.57	-0.01	0.14	0.40
Social stigma	40	People with infertility face uncomfortable views (stigma)		0.14	0.16	0.87	0.03	0.80
-	41	Infertility leads to withdrawal from relationships with people		0.33	0.16	0.81	0.09	0.80
	21	Having a child is an essential social rite of passage		0.23	0.44	0.51	0.16	0.52
Acceptance 17		Infertility must be accepted naturally		-0.03	0.07	0.03	0.74	0.56
	32	As long as the husband and wife agree, infertility should have no significant impact on married life		0.09	0.26	0.00	0.61	0.44
	7	Infertility is not a major problem in life		0.45	-0.05	0.21	0.58	0.59
	26	Infertility is a problem that can be overcome		-0.06	0.27	0.04	0.55	0.40
		Cronbach's alpha	0.90	0.91	0.85	0.77	0.60	
		Eigen value		7.26	2.53	1.33	1.28	
		Explained variance (%)		34.6	12.0	6.6	6.1	
		Comulative (%)		34.6	46.6	53.2	59.3	
		Kaiser-Meyer-Olkin = 0.89 Bartlett's test of sphericity = 1997.07, p < .001						

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underwent confirmatory factor analysis. The model fit was evaluated against predefined cutoff values for each fit index ($\chi^2/df \le 3$, AGFI ≥ 0.90 , GFI ≥ 0.90 , CFI ≥ 0.90 , RMSEA< 0.08) [27]. The model achieved the following fit indices: $\chi^2/df = 2.09$, AGFI= 0.81, GFI= 0.85, CFI= 0.90, RMSEA= 0.07 (Fig. 1).

Multi-trait/multi-item matrix analysis was performed. Convergent validity was validated since the correlation between each item and the total score in the corresponding subscale was 0.59–0.89, which satisfied the cut-off

value of 0.40. Moreover, discriminant validity was also validated since the value derived by subtracting twice the standard error from the correlation coefficient between the item and the corresponding subscale was larger than the correlation coefficient of other sub-components.

Criterion validity testing

Concurrent validity was first tested based on the correlation of the scale with ISS. The results showed a positive correlation with a correlation coefficient of 0.63 (p<.001),

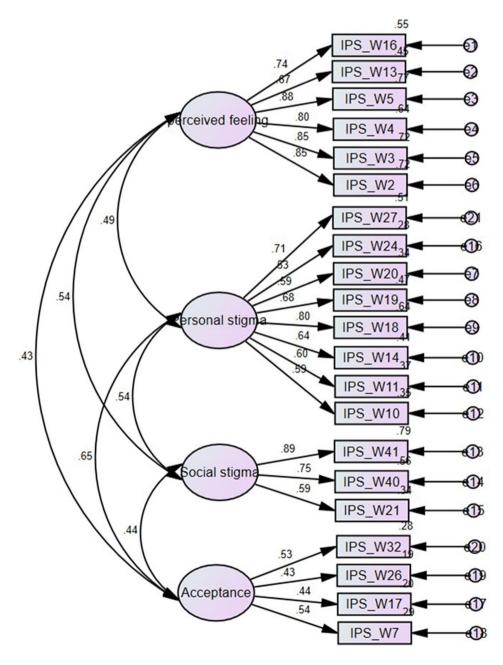


Fig. 1 Measurement model of an infertility perception scale for women (IPS-W). $\chi^2/df = 2.09$, AGFI = 0.81, GFI = 0.85, CFI = 0.90, RMSEA = 0.07 $\chi^2/df = 2.09$, CFI = 0.81, GFI = 0.85, CFI = 0.90, RMSEA = 0.07 $\chi^2/df = 2.09$, AGFI = 0.81, GFI = 0.85, CFI = 0.90, RMSEA = 0.07 $\chi^2/df = 2.09$, AGFI = 0.81, GFI = 0.85, CFI = 0.90, RMSEA = 0.07 $\chi^2/df = 2.09$, AGFI = 0.81, GFI = 0.85, CFI = 0.90, RMSEA = 0.07 $\chi^2/df = 2.09$, AGFI = 0.81, GFI = 0.85, CFI = 0.90, RMSEA = 0.07 $\chi^2/df = 2.09$, AGFI = 0.81, GFI = 0.81, GFI = 0.81, GFI = 0.90, RMSEA = 0.07 $\chi^2/df = 2.09$, AGFI = 0.81, GFI = 0.81, GFI = 0.90, RMSEA = 0.07 $\chi^2/df = 2.09$, AGFI = 0.81, GFI = 0.81, GFI = 0.90, RMSEA = 0.07 $\chi^2/df = 2.09$, AGFI = 0.81, GFI = 0.81, GFI = 0.90, RMSEA = 0.07 $\chi^2/df = 2.09$, AGFI = 0.81, GFI = 0.81, GFI = 0.90, RMSEA = 0.07 $\chi^2/df = 2.09$, AGFI = 0.81, GFI = 0.81, GFI = 0.90, RMSEA = 0.90,

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Table 3 Correlation between IPS-W and ISS (N=203)

IPS-W											
			Perceive	ed feelings	feelings Personal stigma		Social stigma		Acceptance		
	r	p	r	р	r	р	r	p	r	р	
ISS	0.63	< 0.001	0.48	< 0.001	0.53	< 0.001	0.52	< 0.001	0.37	< 0.001	
Self-devaluation	0.62	< 0.001	0.48	< 0.001	0.52	< 0.001	0.50	< 0.001	0.36	< 0.001	
Social withdrawal	0.62	< 0.001	0.54	< 0.001	0.48	< 0.001	0.50	< 0.001	0.30	< 0.001	
Public stigma	0.52	< 0.001	0.36	< 0.001	0.45	< 0.001	0.46	< 0.001	0.32	< 0.001	
Family stigma	0.51	< 0.001	0.35	< 0.001	0.46	< 0.001	0.40	< 0.001	0.31	< 0.001	

IPS-W=Infertility Perception Scale for Women

ISS=Infertility Stigma Scale

Table 4 Comparison of IPS-W according to depression (N = 203)

	Range of	N (%)	IPS-W	
	Score		M±SD	E /n\
			M±3D	F (p)
Depression	0-60			
Normal ^a	0-15	157 (77.4)	42.4 ± 9.1	18.84
				(<0.001)
Probable depression ^b	16-24	23 (11.3)	50.2 ± 10.5	
Definite depression ^c	24-60	23 (11.3)	53.4 ± 9.2	a < b,c

IPS-W=Infertility Perception Scale for Women

while also showing positive correlations between subfactors with correlation coefficients ranging between 0.30 and 0.54. Accordingly, the concurrent validity of the scale was validated (Table 3).

Secondly, the known-groups validity was tested by dividing the subjects into groups by the level of depression based on CES-D cut-off points and analyzing the differences in infertility perception among the groups. Since the results showed significant differences in infertility perception according to the level of depression, the known-groups validity was validated (F=18.84, p<.001; Table 4).

Reliability testing

The Cronbach's alpha value of 21 infertility perception items was 0.90, and for each sub-domain, the Cronbach's alpha value was 0.91, 0.85, 0.77, and 0.60 for Factor-1, 2, 3, and 4, respectively. According to the rationale by Hair et al. [19], a reliability≥0.70 is considered acceptable for any new instrument (Table 2).

Discussion

IPS-W

Factor-1 (perceived feelings) represents overall feelings about infertility, having a total explanatory power of 34.6%. Infertility not only causes psychological distress, such as sadness and loss of hope for the future [4], but it is also defined as an infertility crisis accompanied by physical, economic, and social stress [28]. The 50% of women considered this process as the most stressful experience in their life [29], while 84.2% of Korean women receiving

infertility treatment experienced depression [4]. In Factor-1, the overall feeling about infertility was reflected by negative emotions including a sense of loss, anxiety, despair, depression, sadness, and guilt. Therefore, efforts are needed to understand the negative emotions of people who experience infertility and to alleviate these emotions.

Factor-2 refers to "personal stigma." Infertility can be seen as the fault of the individual, while individuals who experience infertility perceive it as a void and a problem that is difficult to reveal. Personal stigma refers to the extent to which a person believes that negative stereotypes associated with a group they belong to will also be applied to them, while experiencing more personal stigma results in increased self-stigma, which is the feeling that the stigma is applicable to themselves [30]. Factor-2 reflects previous reports that women who marry but have not given birth are stigmatized as not fulfilling the role of a married woman and denying their own femininity [31]. Moreover, infertility diagnosis and treatment endlessly give women existential angst and hoping for a child is perceived as the attempt of women to understand their own existence even if they realize that such hope is in vain [32].

Infertility is understood differently depending on the socio-cultural context. A significant number of women diagnosed with infertility in Korea experience embarrassment and despair from their unexpected difficulties with fertility. Originally, they thought that having a child would be a natural process after getting married, and thus experience confusion about their sense of identity as a woman when this does not happen [33, 34]. The perceptions of the Korean society surrounding infertility has been emphasized as an important factor influencing the sense of identity and emotions of individuals with infertility [35]. In other words, individuals currently undergoing infertility treatment have always perceived infertility negatively, rather than positively, as a member of the society before being diagnosed with infertility themselves. Such perception becomes palpable in their own lives once they are diagnosed with infertility, which

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adds stigmatizing characteristics to their perception of infertility.

Factor-3 ("social stigma") includes stigmatizing characteristics about infertility at the societal level, believing that childbirth are an essential social rite of passage. But as they face difficulties with fertility, the views of other people become uncomfortable to women, leading them to withdraw from relationships. This could be interpreted as a factor similar to the "social withdrawal" mentioned by Fu et al. [12]. This process is well explained by studies reporting that, under the ideology of the Korean society, which regards motherhood as the main definer of a woman's identity and has favorable views on having children, having friends or relatives that perpetrate a negative stigma around infertility and take a cruel view of women regardless of whether they are directly responsible for the infertility [36] can cause women with infertility to withdraw from relationships [33]. In fact, over 50% of Korean women who received infertility treatment experienced prejudice due to infertility and 43% reported serious withdrawal from relationships for this reason [34].

As previously described, infertility is not well understood and not adequately perceived within many societies [37, 38]. Negative social perception about infertility can cause women who experience infertility to internalize social stigma, withdraw from interpersonal relationships, lose self-esteem, and experience decline in quality of life [14]. All items included in Factors 2 and 3 are close to problems stemming from perceived stigma, meaning one's own belief that the society views them as a member of a stigmatized group [39].

Factor-4 reflects "acceptance," whereby infertility is perceived as an acceptable problem that can be overcome together as a couple, rather than a problem that causes a negative outcome in life. Having no child due to infertility and the surrounding stigma can place a serious burden on the couple's relationship and the difficulties may destroy the marriage or strengthen their bond [40]. The perception of infertility is deeply associated with the socio-cultural context due to the longstanding family norms in Korea. Recognizing infertility as a problem that can be overcome and understanding that individuals and the society must work together to resolve the problem.

Meanwhile, Factor-4 had a somewhat low reliability score of 0.60. This could be due to large differences in how positively individuals receiving infertility treatment think about infertility within their socio-cultural and familial context and how significant are their psychoemotional changes, which may vary according to treatment stage, frequency of treatment, and outcomes during treatment (number of follicles, quality of eggs, number of embryos, quality of embryos, etc.). In the future, it may be necessary to repeat the measurements after unifying the infertility treatment on IUI or IVF or using the same

measurement point like the start of treatment rather than during treatment to reduce the factors possibly acting as variables.

Validity and reliability

Concurrent validity test of the developed scale and ISS suggested that a more negative perception of infertility led to a higher perceived stigma about infertility [16, 41]. Moreover, known-groups validity for comparing the level of infertility perception between groups showed that the depression groups perceived infertility more negatively than the normal group, consistent with a previous study [20], which validated the known-groups validity of the scale developed in the present study. The reliability of our scale corresponded to a Cronbach's alpha of 0.90, indicating that the reliability was at an acceptable level and that all items were easily understood by women receiving infertility treatment.

Up to now, while there have been efforts to measure infertility perception, such efforts have focused mostly on the individual's knowledge about infertility diagnosis and treatment or the stigmatizing characteristics of infertility within various socio-cultural contexts. In Korea, in particular, infertility has usually been perceived as having stigmatizing characteristics such as insufficiency and difficulty, but it is important to view infertility as a problem that can be overcome by working together, rather than a negative life event that can destroy the sense of identity of women and cause relationship problems among couples. The newly developed infertility perception scale also includes a significant number of the stigmatizing characteristics of infertility. Hence, efforts are needed to solve the issues surrounding inadequate beliefs through the understanding of the stigmatizing characteristics of infertility in order to transition towards a positive perception of infertility. Infertility not only causes individuals to experience various negative emotions but also impacts their life cycle, potentially increasing the risk of conditions such as coronary heart disease (CHD) [42] and elevating the likelihood of early menopause [43]. Therefore, a positive perception of infertility by those affected directly influences the individual, playing a crucial role in maintaining and promoting overall health.

Strengths, limitations, and future research

This study convenience sampled women receiving infertility treatment at two Korean hospitals specializing in infertility treatment, limiting the generalization of the findings. In addition, although we selected two institutions with similar treatment processes and patient education, there is a limitation in that we were unable to systematically analyze the similarities and differences. Prior to data collection, the authors informed the study participants that the survey was anonymous and that

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their responses would be kept confidential. However, there is a limitation that, due to social stigma, participants might have underreported or misreported their true opinions. Moreover, Cultural differences across countries can significantly influence perceptions of infertility, where what may be considered stigma or acceptable responses in one culture may not be the same in another. Therefore, it is essential to assess the validity and reliability across diverse populations, including different ethnic groups, and adjust the questionnaire accordingly to ensure cultural relevance and applicability. In future research, it is recommended that the validity and reliability of the scale be tested only among women who are at the IVF stage, as IVF is in the final stage of assisted reproductive therapy. Additionally, follow-up studies should aim to identify the level of infertility perception and to develop and test the impact of nursing interventions.

The infertility perception scale developed in the present study could predict the psycho-emotional state of women receiving infertility treatment by examining their infertility perception. These findings could be used for the development of nursing interventions that could help women experiencing infertility to approach positively the problem of infertility.

Conclusions

We developed and tested an infertility perception scale consisting in a 4-point Likert scale with 21 items under four factors. The scale has a score range of 21–84 points, with higher scores indicating more negative perceptions of infertility. The scale can be used to measure infertility perception among women who are experiencing infertility and their spouse, family, and friends. The findings can help nurses provide support that is appropriate for individual circumstances by examining how women experiencing infertility perceive infertility.

Abbreviations

KMO

IPS-W Infertility Perception Scale for Women

IUI Intrauterine insemination
IVF in-Vitro Fertilization
EFA Exploratory Factor Analysis
CFA Confirmatory Factor Analysis
ISI-F Female Infertility Stigma Instrument

ISS Infertility Stigma Scale

STROBE Strengthening the Reporting of Observational Studies in

Epidemiology

CVI Content Validity Index I-CVI Item-Content Validity Index

K-CESD-R Korean version of the Center for Epidemiologic Studies

Depression Scale-Revised Kaiser-Meyer-Olkin

RMSEA Root-mean-square error of approximation

AGFI Adjusted Goodness-of-Fit Index
GFI Goodness-of-Fit Index
CFI Comparative Fit Index

Supplementary Information

The online version contains supplementary material available at https://doi.org/10.1186/s12905-024-03336-0.

Supplementary Material 1

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Author contributions

Conceptualization or/and Methodology: Kim Miok. Data curation or/and Analysis: Ban Minkyung. Funding acquisition: Kim Mioklnvestigation: Ban Minkyung. Project administration or/and Supervision: Kim Miok. Resources or/and Software: Kim Miok, Ban Minkyung. Validation: Kim Miok. Visualization: Kim Miok, Ban Minkyung. Writing: original draft or/and review & editing: Kim Miok, Ban Minkyung.

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Data availability

Datasets used/or analyzed during the current study are available from the corresponding author on reasonable request.

Declarations

Ethics approval

This study obtained an approval from the Institutional Review Board (IRB) of Dankook University (IRB approval no.: DKU 2021-01-022). Consent was obtained from the subjects after informing them about the purpose and procedures of the study and the protection of personal information. Only those who voluntarily consented to participate in the study were included. The subjects were given a small token of appreciation for their participation.

Consent to participate

Informed consent was obtained from all individual participants included in the study.

Consent for publication

Not applicable.

Competing interests

The authors declare no competing interests.

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