Review Article

Perceived Stigmatization, Infertility-related Stress and Quality of Life of Women with Infertility

Maha Gillani[1], Fatima Kamran[1]*, Masha Asad[2], Rafia Rafique[1], Abeer Alkeshnam[3] and Iqra Nazar[1]

[1]*Institute of Applied Psychology, University of the Punjab, Lahore, Pakistan*
[2]*Department of Psychology, Kinnaird College for Women University, Lahore, Pakistan*
[3]*Department of Psychology, University of Kuwait, Kuwait*

*Corresponding Author: Fatima Kamran, Institute of Applied Psychology, University of the Punjab, Lahore, Pakistan.

Abstract

The study aimed to assess the extent to which Pakistani Women seeking infertility treatment perceived themselves as stigmatized. We examined how women with primary and secondary infertility differed in perceptions of quality of life (QOL). A cross-sectional study using purposive sampling technique was used to gather data comprising of (N=122) women seeking treatment for primary and secondary infertility from public sector hospitals and fertility centers of Lahore. Assessment measures included; Demographic and Clinical Information Sheets, Infertility Stigma Scale (Fu et al., 2014), Infertility Distress Scale (Akyuz, Gurhan & Baklr, 2008) and Fertility Quality of Life (Human Reproduction and Embryology & American Society of Reproductive Medicine, 2008). The findings revealed that most of the women with primary infertility (40.2%) reported distressed and stigmatized . Women with primary infertility tend to report increased distress and lower QoL as compared to those with secondary infertility. The findings also revealed that socio demographic factors such as; living in a nuclear family system and older age increased stigmatisation and distress with poorer QoL. Infertility related stress acted as a significant moderator between stigmatization and QoL. The present study adds sufficient data on psychosocial aspects and issues of infertility. The Sociocultural issues and demands placed on women in the subcontinent for child bearing, tend to make them more vulnerable to develop psychological problems. Therefore, psychological screening and monitoring methods may be incorporated in treatment protocols.

Keywords: Infertility; Perceived Stigmatization; Infertility Related Stress; Quality of Life

Background

The span of infertility is continuously expanding in the globe. The issue is not limited to a single area and statistics shows 10-15% couples who are longing for a child but they are helpless. Mascarenhas., *et al.* stated that Middle East, Europe, Asia and Africa ranked on top in infertility [8]. The term infertility is defined by World Health Organization (WHO) as it is the inability of conception of a desiring couple who regularly indulge in intercourse process without using any preventing measures for at least a year of time [16].

American Society of Reproductive Medicine also considers it a disease which cause issues in reproduction process of a couple and unable them to conceive a baby [2]. Gibson and Myers explained two subcategories of infertility as primary infertility and secondary infertility. When the couple failed to conceive their first baby, it is known as primary infertility whereas the failure in conception after first baby is secondary infertility [6]. In Pakistan, 3.9% cases reported of primary infertility, 18% of secondary infertility and the overall percentage of infertility is 21.9% [4]. In short, every 5th

couple, in Pakistan, faces the issue of infertility. According to World Health Organization infertility problems comprise of; 36% tubal issues, 33% ovulatory problems, 6% endometriosis disorders and 40% unexplainable causes [16].

Same ratios of infertility are prevalent in Asia, Latin America, and the Middle East. However, the ratio of unknown factors is 8% to 28% [12]. Infertility has a direct effect on married people in terms of the factors including biological, psychological, and social. As soon as an individual gets married, the society takes him/her as a means of giving birth to the children and starting a family. If there is a case of infertility, the individual has to look for help from outside his/her married life so that he/she can conceive and get pregnant [14].

Society has always negative thoughts about infertility and treats the infertile women with negative behavior and attitude. Even if the infertile problems are due to men but it's obvious in society that women should be responsible for infertility and because of this women has to face a lot of stigmatization and distress that leads to poor quality of life (QoL).

There is limited database in Pakistan in the domain of psychosocial factors related to infertility that has raised concerns among researchers about how can community health be targeted by exploring psychosocial factors related to infertility, and how can they help people in need. Results of the study conducted by Bakhtiyar., *et al.* stated that different components of QoL including physical, psychological, social and environmental health have negatively affected due to infertility [3].

Donkor and Sandall conducted a research to explore how many women experienced stigmatization while getting treatment of infertility and elaborate the existing association between infertility related stress and stigma. Findings of the study indicate that with the increase in stigma, infertility related stress also increases [5]. A study was done in Iran by Nourani., *et al.* revealed that pressure from the society and the family have negative impact on QoL of women with infertility [10].

Hassnain, Raheem and Shahin accompanied a research to assess the impact of infertility on QoL. Findings indicate that primary infertile women significantly scores lower on health related quality of life and sexual functioning with infertility rather than women with fertility [7]. In the light of empirical evidence, it is concluded that women with infertility may experience different psychosocial challenges including stigmatization and infertility related distress that significantly cause impairment in overall QoL.

Objectives

The goal of the current study was to examine women with infertility challenges' self-reports of perceived stigmatization, stress linked to infertility and QoL. We sought to find variations in women with primary and secondary infertility and a range of sociodemographic characteristics in self-reported perceived stigmatization, distress, and QoL.

Methodology
Research design

A cross sectional study design was carried out to investigate how women with primary and secondary infertility tend to report perceived stigmatization, infertility related stress and overall QoL.

Participants

The sample comprised of women (N = 122) seeking regular treatment for primary and secondary infertility, with a mean age of (X = 31.4, SD = 4.12), recruited from private and public sector hospitals in Lahore. Participants were approached and recruited as referrals from gynecologists with the following inclusion exclusion criteria

- Diagnosed with primary (difficulty conceiving a first child after 12 months of unprotected sex), and secondary infertility (the inability to conceive after previous pregnancy, which resulting in still birth or miscarriage).
- A duration of infertility diagnosis for at least 1 year.
- Women with formal education with the ability to read and write
- Not diagnosed or on medication for any other major chronic physical condition other than gynaecological
- Not diagnosed for any psychiatric disorder

Assessment measures
- **Perceived Stigmatization:** Stigma is a term used to describe unfavorable attitudes and beliefs that cause others to dislike, avoid, or fear persons who are perceived to be different. The concern of stigma or of being treated unfairly, which results from societal perceptions of stigma, is known as perceived stigmatization [15].

- **Infertility Stigma Scale (ISS):** In order to gauge how stigma affects women getting infertility treatment. This scale was developed in 2014. The overall scale's Cronbach's reliability was 0.94. The scale has four subscales, 27 items, and measures self-devaluation, social disengagement, public stigma, and family stigma. The Self-devaluation subscale has seven items, followed by five on social isolation, nine on public stigma, and six on family stigma.

- **Infertility related Stress:** Banu defined stress as a difficult pattern of psychological appraisals, physiological reactions, and behavioral predisposition that occur in response to a perceived imbalance between situational demands and our resources needed to deal with them. The term infertility-related stress is explained as the level of such stress perceived by each spouse individually. In the particular context, stress is viewed as a response to a stressful event or stressor, named as infertility [10].

- **Infertility Distress Scale (IDS):** This questionnaire includes 21 multiple choice items which are scaled from 1 to 4, except 5 questions with opposite scaling from 4 to 1. The total scale of 21 items made the overall scale range from 21 to 84. Cronbach alpha value for the scores of items in the measurement tool was found as (0.933) which is higher than the average value [1].

- **Fertility Quality of Life (FertiQol):** The first self-report questionnaire with worldwide validation, called FertiQol, was used to gauge an infertile individual's overall QoL. FertiQol, which is multilingual and takes 10 to 15 minutes to complete, is available in many languages. FertiQol is a 36-item questionnaire that evaluates both core (24 questions) and treatment-related (optional) quality of life (QoL), as well as general life and physical health (2 items). The Core and Treatment FertiQoL (and subscales) had good Cronbach reliability statistics between 0.72 and 0.92.

Procedure

The present study was carried out after approval of ethical protocols of the research. Participants were explained the nature of the study were explained and Informed consent was signed. The Infertility Stigma Scale, Infertility Distress Scale and Fertility Quality of Life questionnaire were administered without any time limit. Demographic and Clinical data was also gathered using self-developed information sheets.

Ethics considerations

The study hospital and doctoral programme committee at the Institute of Applied Psychology, University of the Punjab, gave their approval in terms of ethics. All study participants were given the assurance of confidentiality and were made aware that taking part was entirely optional.

Results

Table 1 provides information about the participant's demographic and medical profile. N = 122 women who were seeking infertility medication completed the questionnaire. The participant's average age was 31.4 (SD = 4.12) years. Secondary infertility affected n = 73, or 59.8%, of the female in present study (Table 1).

Characteristics	f (%)	M (SD)
Age		31.4(4.12)
Education		
High School	09(7.4%)	
Undergraduate	30(24.6%)	
Graduate	67(54.9%)	
Post-graduate	16(13.1%)	
Working Status		
Non-working	100(82.0%)	
Working women	22(18.0%)	
Family system		
Nuclear	78(92.4%)	
Joint	06(7.6%)	
Monthly Family Income		118032(55650.0)
Age at onset of Infertility		25.1(2.55)
Duration of Infertility		6.27(3.42)
Type of Infertility		
Primary	49(40.2%)	
Secondary	73(59.8%)	

Table 1: Demographic and Clinical Profile of the Participants (N = 122).

Measures	K	α	M	SD	Range		Skewness	
					Actual	Potential	Kurtosis	
IDS	21	.78	64.32	11.46	47-100	21-84	.605	2.54
ISS	27	.97	111.4	18.38	65-130	27-135	-1.15	.199
QOL	24	.87	52.27	9.75	37-71	0-96	.912	-.016

Table 2: Descriptive Statistics for Study Variables (N = 122).

Note: k: no. of Items; M: Mean; SD: Standard Deviation,
α: Reliability Coefficient; IDS: Infertility Distress Scale;
ISS: Infertility Stigma Scale; QOL: Quality of Life

The above table describe the descriptive statistics (including mean, standard deviation, range, skewness, and kurtosis) of study constructs. Infertility Stigma Scale showed the highest reliability (α = .97) whereas Infertility Distress Scale (α = .78) and Fertility Quality of Life (α = .87) showed good reliabilities. Alpha values for all measure are in acceptable range. Skewness and kurtosis values are in desire range.

The findings revealed that most women with infertility tend to report moderate satisfaction with their QoL (M = 52.2, SD = 9.67). However, self-reported QoL and stress associated to infertility were found different for women with primary and secondary infertility.

	Primary Infertility (n = 49)		Secondary Infertility (n = 73)				95%CI	
Measures	M	SD	M	SD	T (82)	P	LL	UL
IDS	67.1	11.7	60.9	10.0	-2.55	.01*	-11.05	-1.385
ISS	113	15.4	108.1	22.2	-1.37	.17	-13.82	2.541
QOL	34.4	9.09	42.1	10.06	3.69	.00*	3.580	11.93

Table 3: Independent Sample t Test to Compare Women with Primary and Secondary Infertility in terms of all Study Constructs (N = 122).

Note: IDS: Infertility Distress Scale; ISS: Infertility Stigma Scale; QOL: Quality of Life

The above table shows that women with primary infertility tend to report higher levels of infertility related stress (*M = 67.1, SD = 11.7)* and poorer QoL (*M = 34.4, SD =* 15.4) as compared to women with secondary infertility.

Variables	1	2	3
IS	-	.61***	-.62***
IRD	-	-	-.50***
QOL	-	-	-

Table 4: Pearson Product Moment Correlation between all Study Constructs (N = 122).

Note: IS: infertility stigma, IRD: infertility related distress, QOL: quality of life, p < .05***, p < .01**, p < .001***.

The above table indicates that infertility stigma appears to have a significant positive correlation with infertility related distress (*r* = .61, *p* < .001). The finding reflects that women with negative perceptions of infertility related stigma, tend to report increased infertility related distress.

It was found that women who perceived themselves to be more stigmatized and reported increased infertility related distress appeared to have poorer QoL (*r* = -.50, *p* < .001). It suggests that being more stigmatized and distressed leads towards poorer perceptions of QoL in women with primary and secondary infertility.

Findings of One Way ANOVA suggested that with increasing age, women tend to perceived more infertility related stigma, report increased levels of distress caused by infertility and poor QoL.

Findings of One Way ANOVA suggested that women who had more education were less likely to be stigmatized, felt less distress and reported better QoL.

	Young Adults (n = 37)		Middle Adults (n = 44)		Older Adults (n = 41)				95% CI	
Constructs	M	SD	M	SD	M	SD	F	P	LL	UL
ISS	86.86	5.36	113.2	21.0	114.0	12.90	7.58	.00*	107.2	115.4
IDS	51.14	1.46	61.93	9.60	70.76	11.39	14.4	.00*	62.03	66.97
QoL	50.00	3.41	39.70	10.47	32.58	7.45	12.9	.00*	35.54	39.98

Table 5: One Way ANOVA to Compare Age Differences in terms of Infertility Stigma, Infertility Distress and QoL (N = 122).
Note: IDS: Infertility Distress Scale; ISS: Infertility Stigma Scale; QOL: Quality of Life

Variables	High School (n = 9)		Undergraduate(n = 30)		Graduate (n = 67)		Post-Graduate (n = 16)				95% CI	
	M	SD	M	SD	M	SD	M	SD	F	P	LB	UB
ISS	112.0	.00	121.1	2.45	114.5	16.5	78.7	9.57	41.0	.00***	108.0	114.5
IDS	62.0	.00	72.8	3.83	64.4	12.4	50.8	2.22	18.8	.00***	62.4	66.6
QoL	51.0	.00	49.5	5.77	49.6	8.56	69.5	1.54	36.7	.00***	50.5	54.0

Table 6: One Way ANOVA to Compare Educational Level in terms of Infertility Stigma, Infertility Distress and QoL (N = 122).

Note: IDS: Infertility Distress Scale; ISS: Infertility Stigma Scale; QOL: Quality of Life

Measures	Joint Family (n = 78)		Nuclear Family (n = 44)				95% CI	
	M	SD	M	SD	t (82)	P	LL	UL
ISS	112.4	18.99	97.00	.000	1.982	.05	-.054	30.9
IDS	65.15	11.56	56.00	.000	1.928	.05	-.292	18.60
QOL	56.58	10.22	39.00	.000	4.192	.00***	9.24	25.9

Table 7: Independent Sample t Test to Compare Family Systems in terms of all Study Constructs (N = 122).

Note: ISS: infertility stigma scale; IDS: infertility distress scale; QOL: Quality of Life.

Independent sample t-test shows mean differences between women living in joint and nuclear family systems in self reports of infertility related stress, infertility stigma and QoL. The findings revealed that women living in nuclear family system tend to report lower or poor QoL ($M = 39.00$, $SD = .000$) as compared to those living in joint family system. However, no significant differences were found in reports of infertility related distress and perceived stigma.

In order to investigate the moderating role of infertility related stress in relationship between perceived stigmatization and quality of life, moderation analysis was run using Andrew Hayes Process Macro. Results revealed through analysis are described in table given below

			Quality of Life		
				CI	
	B	SE	t	LL	UL
Constant					
ISS	-.510***	.054	-4.86	-3.69	-.155
IDS	-.200	.089	-1.90	-.345	.007
R²	.421				
F	29.49				
ΔR²	.407				

Table 8: Regression Analysis Predicting Quality of Life in Women with Infertility (N = 122).

Note. ISS = infertility stigma scale, IDS: Infertility Distress Scale; β: Standardized Coefficient, SE: Standard Error; p: Significance Value. *p < .05, **p < .01, ***p < .001, CI: Confidence Interval; R²: R square; ΔR²: Adjusted R square; F: ANOVA

Overall model explained 42% of the variances. Findings revealed that perceived stigmatization (B = -.510, p = .001) negatively predicting quality of life. Whereas, infertility related distress (B = -.200, p = >.05) was not found as a significant predictor of quality of life.

			Quality of Life		
				CI	
	B	*SE*	*t*	LL	UL
Constant	-.629***	.044	4.02	163.9	484.09
ISS	-4.28**	.674	-3.26	-3.54	-.860
IDS	-5.46**	1.54	-2.99	-7.68	-1.54
Interaction (ISS*IDS)	8.09**	.013	2.88	.012	.063
R²	.476				
F	24.21				
ΔR²	.456				

Table 9: Moderation Analysis through Andrew Hayes Process Macro (N = 122).

Note. ISS = infertility stigma scale, IDS: Infertility Distress Scale; β: Standardized Coefficient; SE: Standard Error; p: Significance Value. *p < .05, **p < .01, ***p < .001, CI: Confidence Interval; R²: R Square; ΔR²: Adjusted R Square; F: ANOVA

Overall model explained 47% of the variances. When, infertility related distress entered into the model, interaction term was found to be significant. This finding suggested that infertility related distress has a significant moderating effect on the relationship between perceived stigmatization and QoL.

Overall findings of the current study revealed that women with primary infertility tend to report increased level of infertility related distress and lower QoL. Moreover, sociodemographic factors such as living in joint family system and older age experienced more infertility related stigma and distress with poorer QoL. Furthermore, perceived stigmatization was found to be a significant predictor of QoL. Whereas, infertility related stress appeared as significant moderator in the relationship between stigmatization and QoL.

Discussion

Our research assess the relationship between perceived stigmatization, stress relating to infertility, and QoL to offer light on many facets of the infertility experience for women in Pakistan. It was found that women with primary infertility perceived more stigmatization, greater levels infertility related stress and poor perceptions about QoL. This has also been shown in earlier studies, when stigma was found to significantly correlate with both distress and a low QoL [7]. According to this, infertile women who experienced a lot of stigma were more likely to feel distressed during infertility treatment. In a Pakistani culture, parents and grandparents eager for the grandkids right after marriage and they start exerting pressure on the newly married couple for babies which definitely cause infertility related stress and in this modern era still women from the old generation start stigmatizing the women. This definitely negatively affects women's mental health and QoL. Similarly, Taebi., *et al.* conducted a research in which they found that women with primary infertility tend to perceived higher amount of stigmatization which threatens their psychosocial wellbeing [15].

Results of the present study also revealed that older age women tend to report higher levels of stigma, distress and poor QoL. It is because of the biological fact that it is difficult to conceive a baby in older age or may be women experienced complication in pregnancy, that is why older age women experienced more infertility related stress and stigma due to which their QoL effected poorly [13]. Moreover, findings of the present study indicated that women with infertility, living in joint family system tend to report more stigmatization, higher levels of distress and poor QoL. Family systems shape people's intents through affecting their views on having children and their perceptions of the accepted standards surrounding fertility. This influence has an impact on people's perceptions of

what it takes to raise children and household size, among other things [9]. In Pakistan, most of the married couples tend to live in joint family system that also cause social pressure regarding conception or childbirth due to which most of the women with infertility reported stigmatization, distress and QoL. The finding of the present study is consistent with empirical evidence.

In addition, it was found that women with higher education tend to0 perceived less stigma, felt less distress and better QoL. Donkor and Sandall conducted a research in which they concluded that women with greater educational attainment experienced less distress due to infertility [5]. Moreover, current research found significant correlation between all study constructs. It's quite obvious that there is inverse relationship between stress and QoL. Findings of the present study are in lined with empirical evidence. Findings of the previous study indicates that infertility related stress have negative impact on QoL [11]. Existing literature identified stigma as a significant predictor of QoL [3]. In the light of previous studies, it is concluded that women with infertility experience different clinical or medical complications along with psychosocial challenges that needs to be screened, assessed and managed with aim to promote their better QoL.

Conclusion

In conclusion, women who experience increased stigmatization have poorer QoL. Infertility related stress plays a significant role in moderating perceived stigma and QoL in Pakistani women undergoing Infertility treatment.

The findings highlight the need to address these issues in public health campaigns to minimize the distress these women experience at home with their families and in the larger community, both of which have greater impact on their QoL. In a Pakistani society, higher levels of education can be perceived as a path to and a stand-in for more social and economic power for women. Raising the educational status of women and provision of mental health counsel services may help to improve their QOL.

Bibliography

1. Akyuz A., *et al.* "Development and validation of an Infertility Distress Scale for Turkish Women". *TAF Preventive Medicine Bulletin* 7.6 (2008): 469-476.

2. American Society of Reproductive Medicine. Infertility (2012).

3. Bakhtiyar K., *et al.* "An investigation of the effects of infertility on Women's quality of life: a case-control study. *BMC Women's Health* 19 (2019).

4. Covington SN and Burns LH. "Infertility counselling: A comprehensive handbook for clinicians". Cambridge University Press (2006).

5. Donkor ES and Sandall J. "The impact of perceived stigma and mediating social factors on infertility-related stress among women seeking infertility treatment in Southern Ghana". *Social Sciences and Medicines* 65.8 (2007): 1683-1694.

6. Gibson DM and Myers JE. "Gender and infertility: A relational approach to counselling women". *Journal of Counselling and Development* 78.4 (2000): 400-410.

7. Hassanin I., *et al.* "Primary infertility and health-related quality of life in Upper Egypt". *International Journal of Gynecology Obstetric* 110.2 (2010): 118-121.

8. Mascarenhas MN., *et al.* "National, regional, and global trends in infertility prevalence since 1990: a systematic analysis of 277 health surveys". *PLOS Med* 9.12 (2012): e1001356.

9. Monkediek B and Bras H. "Family Systems and Fertility Intentions: Exploring the Pathways of Influence". *European Journal of Population* 34.1 (2018): 33-57.

10. Nourani SH., *et al.* "Comparison of quality of life in fertile and infertile women referred to the Public Clinics in Mashhad". *Iranian Journal of Obstetrics, Gynecology and Infertility* 15.7 (2012): 24-31.

11. Palomba S., *et al.* "Lifestyle and fertility: the influence of stress and quality of life on female fertility". *Reproductive Biology and Endocrinology* (2018): 16.

12. Quaas A and Dokras A. "Diagnosis and treatment of unexplained infertility". *Reviews in Obstetrics and Gynecology* 1.2 (2008): 69-76.

13. Santos ECM., *et al.* "Quality of life of people living with HIV/AIDS in Sao Paulo, Brazil". *Revista de Saude Publica* 41.2 (2007): 64-71.

14. Sexton MB., *et al.* "Web-based treatment for infertility-related psychological distress". *Archives of Women's Mental Health* 13 (2010): 347-358.

15. Taebi M., *et al.* "Infertility stigma: a qualitative study on feelings and experiences of infertile women". *International Journal of Fertility Sterile* 15.3 (2021): 189-196.

16. World Health Organization. "Department of Reproductive Health and Research". WHO laboratory manual for the examination and processing of human semen, 5th edition (2018).