

## **Quality of life and infertility stigma of infertility couples undergoing in vitro fertilization: a mixed method-based study**

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### **Abstract**

A mixed method study was conducted to explore the quality of life and infertility stigma of infertility couples undergoing in vitro fertilization. (94 couples) one hundred and eighty-eight participants were selected from different fertility centers in Jordan from April to November 2022. To gather the data infertility stigma scale, quality of life scale, and semi-structured interviews have been adopted. Findings of the study showed that the infertility stigma levels were high among the participants, on another hand the level of quality of life was low. Furthermore, the finding presented a strong negative relationship between quality of life and infertility stigma, and the infertility stigma affects a high degree of variance in quality of life. The study presented that the term infertility stigma was perceived as a social, public, family, and environmental stigma.

**Keywords:** quality of life, infertility, stigma, infertility couples, in vitro fertilization.

### **Introduction**

Infertility affects more than 70 million couples in the world. In underdeveloped nations, the prevalence of couple infertility is 6.9% to 9.3%, whereas it is 3.5% to 16.7% in industrialized nations (Zhang et al, 2021). The failure to pregnancy after a year of unprotected and regular sexual activity is known as infertility, it has two forms, the former describes infertility in couples who have never given birth, whereas the second form describes infertility in couples who had at least one previous child (Ying, Wu, and Loke, 2015). The negative effects of childlessness are more severe for infertile couples in developing societies than in developed societies (Fu et al, 2015). It may cause challenges for couples around the world, especially for couples who are typically blamed because of their partner's infertility and experience psychological sorrow and frustration, social rejection (Alhassan, Ziblim, and Muntaka, 2014). Infertility leads to a different form of stigma, in addition to psychological disorders, and potentially unstable marriages because of the perspective of tradition and culture, which puts enormous mental stress on couples (Jing et al, 2021).

Furthermore, Low quality of life, self-devaluation, or social isolation might result from the self-stigma of the infertile couple and their self-humiliation or family members and the general society (Öztürk, Bloom, and Bullock, 2021). An unfavourable psychological attitude known as the stigma has been associated with a variety of harmful outcomes. Goffman's original definition of stigma, given in 1963, was that it transforms a stigmatized person from a complete and normal person to a contaminated, devalued one (Goffman, 1963). It also refers to a negative evaluation of an individual according to a trait that is viewed as out of the familiar and can be

applied to individuals from a variety of backgrounds, including race, gender, sexual orientation, nation, and those with certain psychological or physical health conditions (Golay et al, 2021).

The stigma of infertility is a popular phenomenon that hurts at least two significant life dimensions, self and social stigma (Sum et al, 2020). Corrigan, Kerr, and Knudsen (2005) posit that the two dimensions of stigma have similar affecting, discrimination and cognitive stereotype. However, it's different in that self-stigma refers to poor self-efficacy and self-esteem resulting from internalizing the public stigma, whereas public stigma described the occurrence of large groups of individuals adopting stereotypes against a stigmatized individual (Alemayehu et al, 2020).

A descriptive correlation study by Jing et al, (2022) investigates the stigma, quality of life in the light of fertility, and its factor among Chinese infertile women undergoing in vitro fertilization. Using the scale of stigma and fertility quality of life scale, 588 women who undergo in vitro fertilization were randomly selected. Findings show a significant relationship between fertility quality of life and stigma among the study sample. Furthermore, findings detected that a higher level of stigma can predict a low level of fertility and quality of life. Jing, Gu, and Zhang et al. (2021) investigated the role that coping mechanisms have in modulating the association between fertility quality and the stigma of life in Chinese infertile women who undergo embryo transfer. In a cross-sectional survey, a sample consisting of 768 women who undergo embryo transfer were randomly selected "from Assisted Reproductive Center of Shaanxi Province". For data collection, the researchers used the scales of quality of life, stigma, and coping strategies. Findings presented a negative statistically significant relationship between quality of life and stigma. Through active avoidance, aggressive confrontation, and passive avoidance, stigma had significantly detrimental indirect impacts on infertility quality of life. The meaning-based coping served as a useful middle step. for infertility quality of life, the model accounted for 69.4% of the variation. Zhang et al, (2021) explored the stigma among infertile women in the Zhejiang state, the sample of the study consisting of 270 women who undergo embryo transfer was randomly selected. Chinese translations of the illness information questionnaire and the infertile stigma scale have been used for data collection. Findings showed that Zhejiang women have a moderate to severe stigma towards infertile women. Song et al., (2021) studied the fertility quality of life situation for women receiving frozen embryo transfer. 1062 women in total completed the scale. During therapy, participants acknowledged experiencing a lot of worry and anxiety linked to their fertility. They also experienced lower quality of life issues connected to conception, with the lowest treatment fertility quality of life scores.

Studies on infertility have investigated disclosures, stigma, self-efficacy, and the effect of fertility on quality of life as salient but largely don't associate factors in understanding the nature of self-stigma surrounding infertility. However, no study has considered the concept of self-stigma of infertility couples undergoing in vitro fertilization as predictors of the effect of fertility on quality of life. The stigma associated with infertility is based on a divergence from the social norm to procreate in many nations, including Jordan. Therefore, couples who experience infertility and stigma frequently experience low quality of life. Infertile couples use a variety of strategies to strengthen their marriages and cope with their inability to have children. Some couples seek social support, make efforts to modify the situation and use problem-solving techniques, such as in vitro fertilization-embryo transfer. Jing et al, (2020) and Ergin (2018) revealed that women enduring infertility treatments experience the worse quality of life as well as significant stigma. Monga, Alexandrescu, Katz, Stein, and Ganiats (2004) have demonstrated that infertility and its management may result in stigma, hence

threatening the patient's quality of life, Stigma and a lower quality of life can also cause early treatment discontinuation or treatment resistance. Studies on how stigma affects the quality of life of infertile women receiving undergo in vitro fertilization, however, have not been conducted in Jordan. The current study aimed to explore the quality of life and infertility stigma of infertility couples undergoing in vitro fertilization.

The study's significance comes from the need to more thoroughly examine the complex connection between the quality of life and infertility stigma on the one hand, and infertility couples undergoing in vitro fertilization on the other hand. The current study is the step to respond to the calls exploring the self-stigma can be perceived as a reliable predictor of quality of life among infertility couples undergoing in vitro fertilization, supported by the varied findings of earlier relevant investigations regarding the connection between self-stigma and quality of life.

The current study aimed to explore the quality of life and infertility stigma of infertility couples undergoing in vitro fertilization in addition to examining its predictors. Furthermore, the study tries to get answers about the level of the quality of life and infertility stigma of infertility couples undergoing in vitro fertilization. and to what extent does infertility stigma affect the quality of life of infertility couples undergoing in vitro fertilization? Moreover, to what extent do quality of life and infertility stigma drive infertility couples to undergo in vitro fertilization?

## **Method**

The current study uses a mixed methodology to gather quantitative data and uses qualitative data to provide context for the quantitative findings. In order to collect the quantitative data two scales have been used. Furthermore, to gather qualitative data semi-structured interviews have been adopted. (94 couples) one hundred and eighty-eight participants aged from 30 to 45 years were selected from different fertility centers in Jordan from April 2022 to November 2022. The participants come from different towns and cities and are representatives of all Jordanian socioeconomic classes. The study has adopted an infertility stigma scale (Fu et al., 2015) consisting of 27 items divided into four dimensions' social withdrawal (5) items, family stigma (6) items, self-devaluation (7) items, and public stigma (9) items. The scale was developed to measure the perceptions of couples who receive infertility treatment-related stigma. Furthermore, the scale graded according to the fifth Likert format rating from strongly agrees = 5 to strongly disagree = 1. Moreover, the study adopted the World Health Organization's quality of life scale (2012 revision). The scale consists of (26) items divided into psychological health (6) items, physical health (7) items, environmental health (8) items, and social relationship (3) items. The scale grade according to the fifth Likert format rating from extremely = 5 to Not at all = 1.

The internal consistency as the correlation coefficient between the score of every item and the total score of the scale has been calculated for two scales. Findings showed that the items of the two scales were statistically significant at ( $\alpha \leq 0.01$ ). which means that the items on the scales are internally consistent. Another analysis was Alpha Cronbach which reflects that the values of infertility stigma range between 0.80 to 0.84, and values of quality of life range between 0.81 to 0.86. Furthermore, discriminant validity has been examined: when the participant's grades were divided into two groups and sorted by decreasing order, 27% of the highest grades were considered to be in the highest group and 27% of the lowest grades were in the lowest group. To investigate the difference between the two independent categories, a t-

test has been calculated. Findings illustrated significant differences between the two groups in both scales, reflecting the scales' discriminant power.

Official approval has been obtained from the officials of the designated centers to collect information and data from the sample of the study. Then, the infertility couples' contact numbers have been collected, and were invited to participate via WhatsApp with information about the study attached. A one-week time allowance was given to reflect upon the invitation before making a follow-up mobile call. After reaching an agreement with the participants, the online survey based on Google form was sent to them through WhatsApp. Later, each participant asked for the time and location of their preferred interview. Interviews were held in fertility centers place that permitted total privacy and confidentiality to guarantee the comfort, quality, and uninterrupted flow of the interviews.

A formal consent form was given, in addition to introductory questions, "What is stigma and quality of life?" and "How does affect the individual and social context?" formed the basis of the semi-structured interview questions. Participant comments guided the direction of subsequent questions. Most talks, however, focused on the severity and effects of stigma on quality of life the many kinds of discrimination and/or stigmatization, and the demographic groups who experience stigmatization the most. The interviews typically came to an end with a discussion of potential approaches to combating discrimination and stigma, every interview was taped, then the transcription was done. The duration of each session was ranging between 30 to 40 minutes.

## Results

To explore the level of the quality of life and infertility stigma of infertility couples undergoing in vitro fertilization. An Independent sample test was run as described in the below table (1).

**Table 1:** *One-sample t-test for the scales and their dimensions.*

Scales	Dimensions	Mean	St.dev	t	Sig
infertility stigma	social withdrawal	3.95	0.71	1.34	0.00*
	family stigma	4.38	0.68	2.03	0.00*
	self-devaluation	4.26	0.73	2.92	0.00*
	public stigma	3.88	0.63	2.82	0.00*
Quality of life	psychological health	2.82	1.95	1.14	0.07
	physical health	3.14	0.817	1.61	0.00*
	environmental health	3.10	0.91	1.66	0.00*
	social relationship	2.69	1.98	1.76	0.10

\* Sig at ( $\alpha \leq 0.05$ )

Results in table (1) illustrated the infertility stigma dimensions were high and statistically significant at ( $\alpha \leq 0.05$ ). This would designate that the level of infertility stigma was high among infertility couples. Furthermore, the results find out the quality of life dimensions' score was about moderate among infertility couples. Finally, results showed that psychological health and social relationship as a sub-dimension of quality of life did not detect any significance at ( $\alpha \leq 0.05$ ) and were the lowest among the participants.

In order to examine to what extent does infertility stigma affect the quality of life of infertility couples undergoing in vitro fertilization? Person correlation and simple linear regression analysis have been calculated as indicated in the table (2 & 3).

**Table (2): Pearson Correlation coefficient.**

Variable	Quality of life
Infertility stigma	- 0.67**

\*\* Sig at ( $\alpha \leq 0.01$ )

Table (2) disclosed a strong negative significant relationship between infertility stigma and quality of life ( $r = - 0.67$ , sig = 0.01).

**Table (3) simple linear regression analysis**

Independent variables	Dependent variable	Constant	f	R	R <sup>2</sup>	Beta	t
infertility stigma	Quality of life	2.83	9.79	-0.64	0.65	-0.64	0.98*

\* Sig at ( $\alpha \leq 0.05$ )

Table (3) showed the simple linear regression analysis indicated that infertility stigma negatively significance correlated at ( $\alpha \leq 0.01$ ) with the quality of life of infertility couples. Moreover, ( $R^2 = 0.65$  and Beta = - 0,64) reflects that the infertility stigma affects (65%) of the variance in quality of life.

To investigate to what extent quality of life and infertility stigma drive infertility couples to undergo in vitro fertilization.

Semi-structured interviews have been conducted to find data and answers to what extent quality of life and infertility stigma drive infertility couples to undergo in vitro fertilization. Couples in each case were interviewed separately after the collection of the descriptive data. Besides, further, explain the factors that would increase the stigma or hinder the quality of life level among the participants. the interviews examine how the couples perceived the influence of stigma on the quality of life and how stigma and quality of life drive them to undergo in vitro fertilization. The objective of the interviews was to verify the data of quantitative and to examine in-depth information, and details, and further explain the data. The subject examined in the interviews dimensions and factors that would increase stigma or hinder the quality of life; moreover, the influence of stigma in driving the couples undergoing in vitro fertilization; the challenges of infertility; and how to improve the quality of life. The interviews were analyzed to verify the designed themes within each case and categorize the differences and similarities between the cases.

## Infertility stigma themes

### *Public stigma*

Most of the responses in the two cases believed that infertility could deprive couples of mental health, as well as lead to sadness, worry, stress, feelings of guilt, and issues with family and social relationships. It may also cause decreased self-esteem, psychological disturbance, low self-efficacy, and a tendency toward self-stigma. (Participant X with 9 years duration of marriage expressed that the social conventional culture holds that if a person is childless, their home is empty).



### ***Social withdrawal***

Most of the participants believe that infertility is related to social stress influencing all the dimensions of couples' lives and quality of life. Moreover, verbal stigma in the form of sarcasm, embarrassment, and the use of derogatory phrases for infertility by acquaintances was one of the distressing behaviors that all the couples highlighted. Furthermore, the attitude of members of society and their negative points and ideas toward infertility was pointed out by most couples. (Participant H with 8 years duration of marriage noted that I can tell what they're thinking from the way they look. I'm not at all bothered by infertility, but I am by their appearance). In another case (participant M with 5 years duration of marriage expressed that people have diverse opinions about you. It appears that you are abnormal).

### ***Self-devaluation***

Most of the participants avoided using the word infertility. They frequently used the issue or difficulty of the term. Moreover, most participants faced a lot of intrusive inquiries from their friends, such as: Why don't you have kids yet? Do you or your hubby struggle with anything? the couples thought these queries were intrusive and irritating. (Participant Y with 7 years duration of the marriage, said that it's psychologically awful that you are so inept that you were unable to give your partner a kid)

### ***Family stigma***

Most of the participants expressed that they are exposed to stereotypes of shame, blame, public attitudes, and contamination, which blame family members for incompetence. the family may resort to social self-limitations, and the family may also hide their infertility relative, which may lead to delay in discrimination from getting services, and treatment seeking, and. All these factors may cause a low quality of life. (Participant R with 12 durations of marriage said that when my mother introduces me to others, she says: she is our daughter, she has been married for 13 years but still doesn't have kids. Please pray for her. In this state she wants to damage me and claim that I am to blame for the issue).

## **Quality of life themes**

### ***Psychological health***

Most of the participants' experiences revealed their anguish and despair. Repeated inquiries from friends would result in mental distress. Bitterness, grief, and anxiety were the negative emotions these infertile couples described. In addition, the women were preoccupied with infertility and its possible effects, including the likelihood of the husband's divorce and subsequent remarriage. Despite their spouses' backing, many feared their marriages would fail. They had always worried that not having a child will make their husband bored with them. (Participant N with 5 years duration of marriage noted that infertility, in my opinion, is a catastrophe. The condition itself may be treatable, but our society's events and how people treat us are horrible. The fact that everyone ascribes blame to you put me under psychological stress, in addition to my response to infertility frustration, shock, depression, sadness, anger, and loss of self-confidence and self-esteem).

### ***Physical health***

Most of the participants presented that the main symptom of infertility is most of the women with infertility may have an absent or irregular menstrual cycle. In some cases, men with infertility may have some hormonal problems, such as changes in sexual function or hair growth. (Most of the female participants said I occasionally experience irregular or non-

existent menstrual cycles. My husband occasionally displays symptoms of hormone imbalances, such as changes in hair growth or sexual behavior).

### ***Environmental Health***

Most of the participants expressed that, for optimum health, we require secure, supporting environments. Living conditions play a significant role in determining our health and happiness. We are dependent on the environment that supports life such as the quality of life that is affected by environmental: social, physical, chemical, biological, and psychosocial factors. (Participant R with 10 years duration of marriage indicated that I've always believed that I am inferior to others since I am unable to become pregnant or have children. This concept annoys me).

### **Social relationship**

Most of the participants described that society treats infertile couples with disdain and humiliation because it believes that their infertility is retribution for some social sins. Social rejection, verbal and physical violence, as well as divorce, were among the social effects of infertility. Furthermore, infertile couples avoided social gatherings, including those hosted and planned by their own family. (Participant S with 9 years duration of marriage noted that I don't feel comfortable at social activities and parties at all. I have a bad feeling. my self-concept has seriously decreased. I dislike being among other people. in comparison to them, I feel dull).

### **Discussion**

The current study is one of the few studies that focus on exploring the Quality of life and infertility stigma of infertility couples undergoing in vitro fertilization in Jordan based on a mixed-method study. Findings of the study showed that the infertility stigma levels were high among the participants, on another hand the level of quality of life was low. Furthermore, the finding presented a strong negative relationship between quality of life and infertility stigma, and the infertility stigma affects a high degree of variance in quality of life. The study presented that the term infertility stigma was perceived as a social, public, family, and environmental stigma. Infertility stigma was experienced as negative evaluation and feelings. In contrast, the participants of the study claimed that their family friends and society had verbally degraded them by calling them sterile, issueless, and futile. couples can only improve their quality of life and status in the family and society by having children. Having children is one of the most significant duties of women in traditional societies, and those who are infertile are weak in the points of view of other people and would suffer stigma and low quality of life.

Based on the interviews, couples may internalize the stigma and perceive themselves as inferior to other couples. They experience low quality of life and social isolation, moreover, couples have reported feelings of social isolation, low self-esteem, and feelings of worthlessness and losing control. couples also mentioned that infertility would endanger their marriage. Furthermore, they have also been a reported fear of divorce. The findings of the current study agree with the previous studies which have been conducted by Jing et al, (2022) findings show a significant relationship between fertility quality of life, and stigma among the study sample. Furthermore, findings detected that a higher level of stigma can predict a low level of fertility and quality of life. In addition, the study of Jing, Gu, and Zhang et al. (2021) presented a negative statistically significant relationship between quality of life and stigma. And a study by Song et al., (2021) acknowledged

experiencing a lot of worry and anxiety linked to their fertility. They also experienced lower quality of life issues connected to conception, with the lowest treatment fertility quality of life scores.

Although the nature of the qualitative study means that its conclusions are largely context-dependent, they are probably generalizable to groups with similar characteristics in other similar environments. The study's inability to examine the experiences of infertile couples who were not referred for treatment is one of its limitations. The current study shows a clear image of infertility stigma and the quality of life of infertility couples, it could be a departure for further studies related to the quality of life and infertility. It could also be used for building psychotherapy programs for counselling, psychological, and interventions suitable for infertile couples.

## **Authors' contributions**

Alkhutaba conceived the idea, developed the theory, performed the computations, verified the analytical methods, and supervised the results. Alkhateeb explored a target sample. The two authors discussed the results and contributed to the final manuscripts.

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