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Infertility: A Sociological study with Reference to Quality of Life of Victims of infertility in Chennai City

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Abstract : *The effects of infertility vary among societies and between men and woman. Understanding the Quality of Life of victims of infertility will help in developing many societies and overcoming the issues, which would benefit the couples. The study has made an attempt to analyse the problems faced by the victims of infertility. QOL related to health is a vital method to determine the outcome measurement of victims of infertility. Determining the physical, psychological, social, relational and other inappropriate effects of infertility would help in planning to improve the QOL. For the study purpose 100 respondents were chosen by using convenient sampling from selected fertility centres through inclusion and exclusion criteria for collecting data. The objectives of the study are to get the demographic profile of victims of infertility, assessing the QOL of people living with infertility, and analysing with reference to the four domains (physical, psychosocial, social relationship and environment). The study is descriptive in nature with both qualitative and quantitative. FertiQoL tool was used to assess the QOL of such victims. The study has reported one of the findings that respondents who perceive more social support have better QOL scores across emotional, instrumental and support from institutions. Further, the findings highlighted that women are the most affected group as evidenced by lower QOL scores. The FertiQoL includes mind and body (physical health), emotional health (psychological health status), social health (social and relational aspects), environmental aspects and tolerability to the treatment processes. The recommendations provided for this study are very much relevant for developing schemes and policy implementations.*

Key words: *Infertility, QOL, FertiQoL, Physical health, Psychology, WHO, Stress, Livelihood.*

1. INTRODUCTION

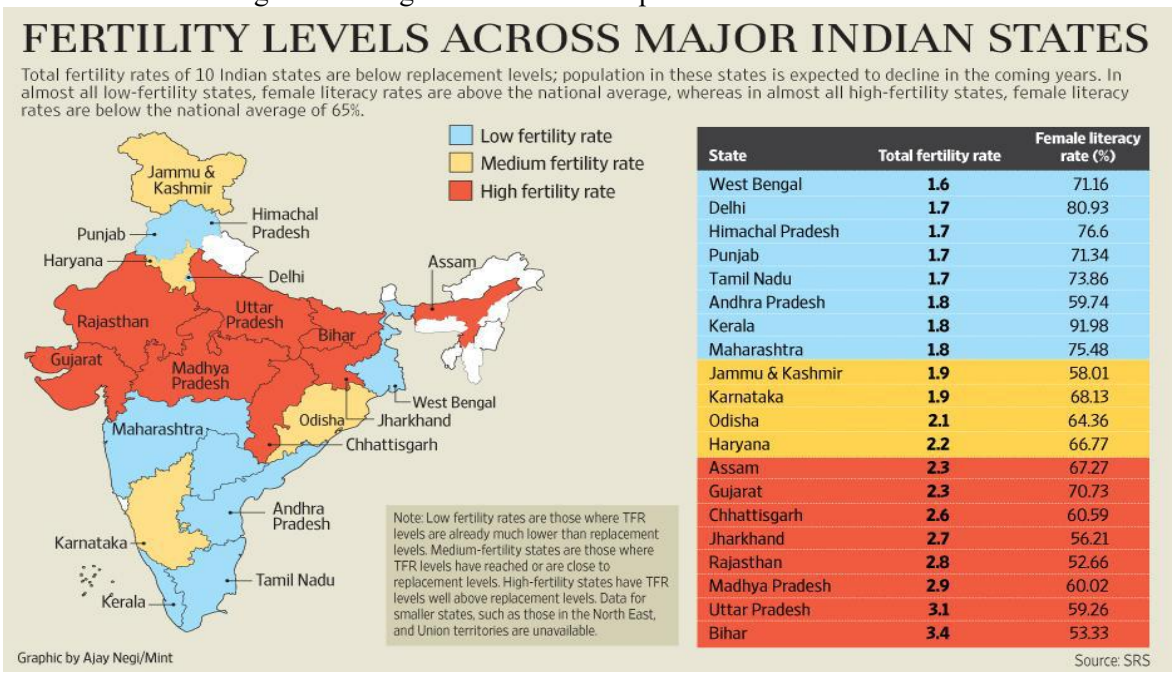
In the 21st century, childlessness or infertility remains as a global burden. Nearly 180 million people suffer from primary or secondary infertility, worldwide. The demographic definitions of infertility by WHO (2010) states “a disease of the reproductive system defined by the failure to achieve a clinical pregnancy after 12 months or more of regular unprotected sexual intercourse”. Gurunath et al (2011) reported in the article “Defining Infertility - A Systematic Review of Prevalence Studies” that subfecundity is defined as “prolonged time to pregnancy and difficulty in carrying the pregnancy to live birth”. Never attaining conceived is primary infertility and on other, unable to conceive after having previous successful pregnancy is known as secondary infertility.

The WHO has defined QOL as the perception of individuals with regard to their positions in life in the context of their cultural and value systems in which they live in and in relation to their goals, expectations and standards in life. To put in simple words, fertility-related QOL is the general wellbeing of people who live with infertility, which includes physical, psychological, social, emotional, relational and environmental wellbeing. It also relates to the tolerability to infertility treatment among both men and women. The WHO (2009) defines “Quality of life as an individual’s perception of their position in life in the context of their culture and value systems in which they live and in relation to their goals, expectations, standards and concerns. It is a broad ranging concept affected in a complex way by the person’s physical health, psychological state, personal beliefs, social relationship and relationship to the person’s environment”.

Ombelet.W (2014) reported in his publication titled "Global Access to Infertility Care Reality, The Walking Egg Project" that there are differences in the scenario of childlessness between the developed and underdeveloped countries. The discrimination in the rates of infertility between nations is due to the availability of treatment options and the expenditure towards treatment. It is generally believed that infertility diagnosis takes a longer time and is very expensive, and the couples who suffer from infertility undergo a lot of stress. Three global infertility survey results are available which were published in 2004, 2007 and 2012, with varying results. The average range of the rates is documented as 48.5 to 186 million people with infertility, worldwide. Further, the author reports that women from low-income countries suffer from a higher percentage of secondary infertility. Another reality statement by the same author is that the highest rate of infertility in countries around the world is less likely to provide appropriate diagnosis and treatment, which includes IVF, which may lead to reproductive health disparity. Keramat et al (2014) reported in the article titled "Quality of Life and its Related Factors in Infertile Couples" and presented the following. The effects of infertility vary among societies and between men and woman. Understanding the QOL of people with infertility will help in developing many studies and overcoming the issues, which would benefit the couples and society. QOL related to health is a vital method to determine the outcome measurement in people living with infertility. Determining the physical, psychological, social, relational and other inappropriate effects of infertility would help in planning to improve the QOL. The main aim of the study is to get the demographic profile of people living with infertility, assess the QOL of people living with infertility, and assess with reference to the four domains (physical, psychosocial, social relationship and environment).

1.1 The Indian Scenario on Infertility

India has a high infertility rate, with over 22 to 33 million people having lifetime infertility. Even though the fertility rates in India are consistent with other countries, the skewed demographic profile directs towards the youth population and exposure to risk factors of infertility decreases the fertility rate. The male factor contributed to 30-40% of infertility proportion. There was an increase of 14% in the percentage of women in the reproductive age group of 20 to 44 years. Since 2010, there has been a hike of 20% in the percentage of women aged between 30 to 44 years, and they are the group who represent the low fertility rates. The increase in the use of contraceptive devices and the appearance of risk factors may further increase the burden of infertility rates in India. The risk factors which contribute to infertility in India have been documented in many surveys via national health family surveys and Census India, 2011. These surveys point out that polycystic ovary syndrome (PCOS), endometrial tuberculosis, obesity, alcohol intake, smoking and tobacco use and sexually transmitted infections are the major factors leading to Infertility. Adamson et al (2011) in the article titled "Prevalence & Correlates of Primary Infertility Among Young women in Mysore, India" reported the following. The rates of infertility in India differ in various states. Rates of infertility were 3.7% in Uttar Pradesh, Himachal Pradesh and Maharashtra, 5% in Andhra Pradesh and 15% in Kashmir. Couples with infertility are reported to have low self-esteem and negative feelings and unrealistic expectations.



State	Total fertility rate	Female literacy rate (%)
West Bengal	1.6	71.16
Delhi	1.7	80.93
Himachal Pradesh	1.7	76.6
Punjab	1.7	71.34
Tamil Nadu	1.7	73.86
Andhra Pradesh	1.8	59.74
Kerala	1.8	91.98
Maharashtra	1.8	75.48
Jammu & Kashmir	1.9	58.01
Karnataka	1.9	68.13
Odisha	2.1	64.36
Haryana	2.2	66.77
Assam	2.3	67.27
Gujarat	2.3	70.73
Chhattisgarh	2.6	60.59
Jharkhand	2.7	56.21
Rajasthan	2.8	52.66
Madhya Pradesh	2.9	60.02
Uttar Pradesh	3.1	59.26
Bihar	3.4	53.33

Source: Secondary data

1.2 The Tamil Nadu Scenario on Infertility

The infertility rate in Tamil Nadu has increased to an alarming stage as reported by Deccan Chronicle news magazine (July 21st, 2015) based on the national symposium report by Aakash Fertility Centre. The article reported that 20% of couples are diagnosed with infertility. The report also emphasised that 70% of the causes and risk factors are preventable and require further ART treatment. Shamila et al (2011) in their article titled "Primary Report on the Risk Factors Affecting Female Infertility in the South Indian Districts of Tamil Nadu and Kerala" reported the following data. The infertility rate in Tamil Nadu was 20%, while it was less in other North Indian states due to early marriages and lower literacy rates. In the Kanyakumari district, the infertility rate was 45.67% among women and 54.33% among men. The majority of the infertility cases (82%) were in the primary infertility category and 18% in the secondary category. The rate of infertility in Tirunelveli district was 41.91%. The report from the GG Fertility Centre, Chennai, showed an alarming rate of 3000 new patients with infertility per year; the patients were from different regions of Tamil Nadu and other parts of the country.

1.3 Quality of Life of victims of infertility

Namdar et al (2017) published an article "Quality of Life and General Health of Infertile Women" and reported the following. Infertility and problems with mental health are related to each other. Infertility results in couples going through difficult experiences. It has been reported from numerous studies that infertility brings in a lot of social factors, which has an influence on the attitude about infertility among the society and affected groups. Therefore, it is essential to study the health-related QOL among the affected population.

2. Review of related literature

Patel et al (2016) published an article named "Sociocultural Determinants of Infertility Stress in Patients Undergoing Fertility" and reported the following. A study was done in Manipal, India, to determine the proportion and indicators of stress among men who have been diagnosed with primary infertility. This study aimed to explore the life experiences of men with infertility and predict their stress factors. This study utilised a cross-sectional research design and included 300 men as respondents of the study. The tools used to collect the socio-personal variables in this study were developed by authors, along with the psychological evaluation tests. The findings of the study reported that the stress experienced by men would lead to serious mental health issues. Further, the study recommended that fertility clinics in India should identify this stress as a recognisable one and develop interventions to alleviate the stress factor for successful outcomes.

Shlomo et al (2017) published an article titled "Life Satisfaction of Women in Early Stages of Fertility Treatment" and reported the following. This study assessed the associations of perceived stress, cognitive appraisal, and self-adjustment to the life satisfaction of women, who were undergoing infertility treatment in their early stages. The samples were taken over a period of 18 months. The findings of the study revealed that women had a higher level of self-mastery and a lower level of stress with greater life satisfaction. The relationship between self-mastery and cognitive appraisal to threat and self-efficacy was associated with perceived stress. The study recommended that infertility clinics should plan interventions that concentrate on relieving the psychosocial stress among women being treated for infertility.

Dadkhah tehrani et al (2018) published an article titled "Association Between the Religious Coping of Infertile People with their Own Quality of Life and Their Spouses: A Correlation Study in Iranian Infertile Couples" and presented the following details. The religious coping among infertile couples and their association with life satisfaction was investigated through a correlational study in Iran. The study included 200 women who were attending fertility clinics in Iran. The findings of the study showed that religious coping strategies among infertile women were positive with life satisfaction. The study concluded that there was no marked difference in the relationship of religious coping scores with the spouses' QOL scores with other spouses in infertile couples and recommended future research involving other religions.

Ram (2006) published their article titled "Childlessness and its Consequences in India : Levels, Patterns and Differentials" and presented the following information. The author has cited from various sources that infertility threatens the survival of the family, and childlessness is often considered a tragedy. Another study done internationally reported that infertile men are prone to developing loneliness, ill health and depression.

Barua et al (2014) in their article titled "Infertility Concerns among Young Couples in Rural India" investigated the effectiveness of community-based programs for infertile couples in Maharashtra, India. The health education sessions in the program discussed the definition of infertility and gave suggestions as to when medical treatment should be sought if couples don't conceive within three years of regular sexual intercourse, without use of contraceptives. As per the report of the authors, women who are married and do not have children within one year are not respected and are harassed by their in-laws. Some of the women face neglect and violence and are constantly blamed for being childless; some women are forced to agree to their husbands getting married again. From this report, we can understand that women face more problems because of childlessness and it requires policy changes in the health sector for appropriate treatment facilities related to infertility. We can come to an understanding that the awareness sessions in the fertility or reproductive health clinics are not complete in its nature, and couples and families need a detailed awareness program on modifiable factors of infertility, thereby reducing the burden of infertility in society.

3. Statement of the Problem

In both developed and developing countries, family holds society together, and so parenthood plays a major role in a family being happy. Good QOL is achieved by men and women becoming parents. Primary infertility is often high, with many issues in the family, when compared to secondary infertility. The causes are genetic in both men and women. However, in many cases, the Etiology is unknown. Primary infertility, other than affecting physical health, also creates stress on the family due to various factors like psychological health, social relationship and environment. In recent years, progress in medical technology has offered hope to many couples with infertility, especially in the developed world. However, the progress that has been made has raised new medical, ethical and social issues, which requires attention not only from health professionals, but also from society as a whole.

3.1 Significance and Need for the Study

Many studies have been documented universally to understand the impact of infertility. It's a challenge for the researcher, as it is a very sensitive issue to deal with. According to a Times of India News magazine reported by Kalpana Sharma (2018), there are 27.5 million couples in India undergoing distress due to infertility. There are a lot of reasons being quoted for the infertility status in India, ranging from increased use of contraceptives, medical conditions and lifestyle, age of women, male factors, and most importantly - stress. An in-depth understanding of the QOL of couples will facilitate healthcare workers to develop interventions, which can reduce the amount of stress they undergo and improve their QOL. The importance of assessing QOL was considered crucial to clinical practice, and so it was decided there will be a detailed study on QOL.

3.2 The following objectives are listed out here for present study

- To study the socio-economic and the demographic profile of the people living with infertility in the selected fertility centres.
- To assess the infertility with reference to physical health, psychological health, social relationship and environment.
- To assess the perceptions of people living with infertility concerning Quality of Life (QOL).

4. Research Methodology

A descriptive survey approach was used to assess the socio-economic and demographic profile of the victims of infertility in a selected hospital of Chennai city. The four domains - physical, psychological, social and environmental - were used to evaluate the QOL of respondents from the study area.

4.1 Inclusion Criteria followed in selection of samples

- Respondents who were diagnosed with primary infertility
- Respondents (male/female) available during the time of data collection
- Respondents (male/female) willing to participate in the study
- Respondents (male/female) undergoing treatment for infertility

4.2 Exclusion Criteria followed in selection of samples

- Respondents (male/female) who have secondary infertility, having a child and undergoing treatment for another child

- Respondents (male/female) who have chronic health conditions like asthma, diabetes, physical disability and mental illnesses like depression and psychosis.

4.3 Pilot Study

The pilot study was done with 10% of the samples in the two hospitals, after obtaining the necessary permission from both the hospitals and informed consent from the respondents. The study was done for one week, using the same interview techniques and FertiQoL. The findings of the pilot study proved that it was feasible and practicable to proceed with the main study.

4.4 Variables used for the Study

The present study has been used with independent variables - age, sex, income, education, occupation, religion, nutritional status, menstrual pattern and contraception. The study has been used with dependent variables also such as - mind/body/physical domain of FertiQoL, emotional and relational (psychological) domain of FertiQoL, social and environmental domain of FertiQoL and overall perception of FertiQoL

4.5 Sampling

100 respondents belonging to a cross-section of the population of the two fertility centres were selected using convenient sampling technique to assess the QOL of people living with infertility. Out of the 100 samples, 63 were female respondents and 37 were male respondents.

4.6 Data Collection

There are four domains namely, physical health, psychological health, social relationship and environment. The purpose of the questionnaire was explained to participants and they were asked to fill in the questionnaire. A face-to-face interview was conducted to gather information on demographic data and FertiQoL. It took around 30-40 minutes for each participant to collect the data. The participants were interviewed after getting informed consent and confidentiality was maintained.

4.7 Data Analysis and Interpretation

Secondary data were collected from related articles, hospital administration records, doctors, gynaecologists, fertility centres, and nursing leaders. Based on the criteria, respondents were selected to observe their QOL. The primary data consist of 37 male and 63 female were used as tool for data collection from selected fertility centres.

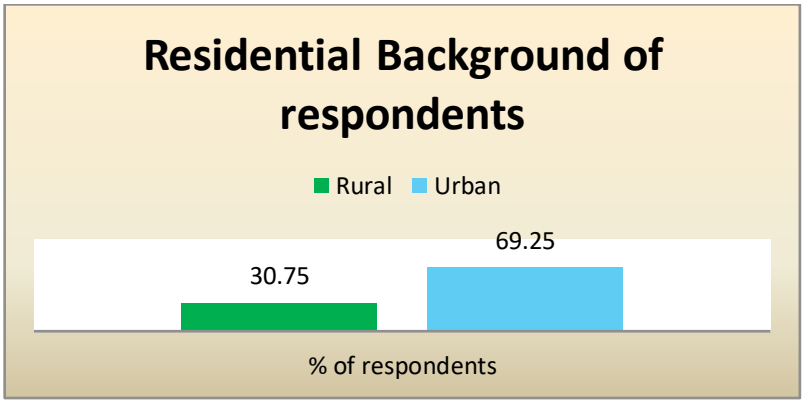
4.8 A DEATILED DISCUSSION ON PRIMARY DATA

Table: 1 Monthly Income of Respondents

S.NO	Monthly income/ INR	No. of Respondents	Percentage
1	Below 10,000	2.75	2.75
2	10,001-20,000	11.25	11.25
3	20,001-30,000	40.75	40.75
4	30,001-40,000	29.25	29.25
5	40,001-50,000	5.00	5.00
6	50,001 and above	11.00	11.00
	Total	**100**	**100**

The above table depicts the monthly income of the respondents (together if both the husband and wife are working). Most of the respondents (40.75%) earn between 20,001-30,000 INR Per month, 29.25% of respondents earn 30,001-40,000 INR per month, 11.25% of them earn 10,001-20,000 INR per month and 5.00% earn between 40,001-50,000 INR per month. Around 11.00% of respondents have a monthly income of above 50,001 INR per month; these respondents are working in the IT sector and other private organisations. Only 2.75% of respondents have a monthly income of less than 10,000 INR. A study done by Adamson et al (2011) reported that family income correlated with infertility in Mysore, India. The author reported that the mean income of families with infertility was 2892 INR per month. The monthly income of women who were infertile were higher than that of the fertile group at $P<0.05$ levels. The current study shows that the monthly incomes of the respondents are mainly between 20,001-30,000 INR, which is a decent income to run a family, but not quite enough to afford expensive infertility procedures. Nearly one-third of the couples have high to very high salaries, indicating that they would be able to afford the ART procedures. Both the infertility centres selected for the study are private fertility clinics, which use advanced and expensive methods to treat infertility, which would make it difficult for couples with single income or less than 10,000 INR per month. It would be beneficial for couples if they could get financial help from their Government.

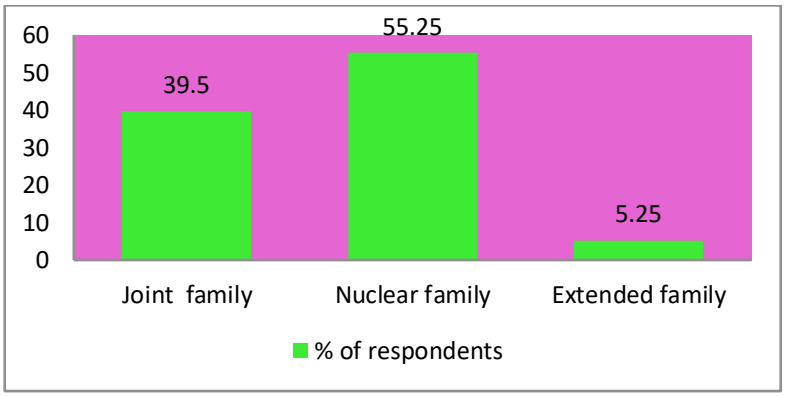
Fig.1: Residential background of Respondents



Source: Primary data

The above illustration reveals the residential background of respondents. The majority of respondents (69.25%) are from urban settings and the rest of them are from rural areas. These data were not used for comparing any variables but used as a baseline data. As the fertility centres are located in Chennai, people come from different places and hence the data is expected to be very usual.

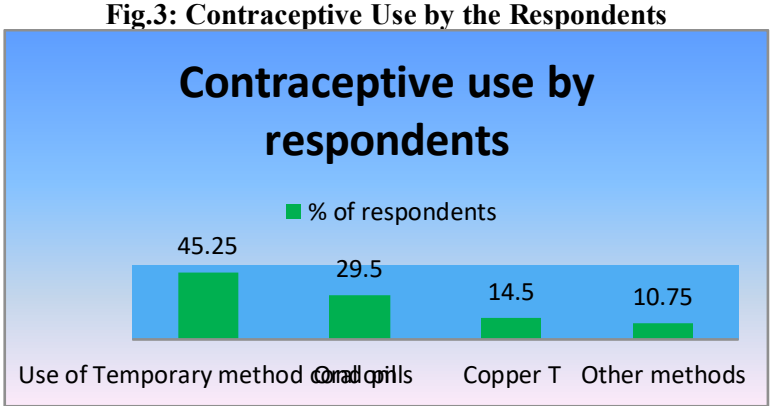
Fig. 2: Family type of the Respondents



Source: Primary data

The majority of the respondents (55.25%) belong to a nuclear family, 39.5% live in a joint family and 5.25% live in an extended family. A similar finding with regard to family type among infertile couples was reported by Mohammed et al (2012). The author reported that 42.6% of respondents were from a nuclear family and 45% were living in an extended family. The variation in results may be because of the recent trend in India, where married couples and families opt for living in a nuclear setup due to workplace proximity and other issues.

Fig.3: Contraceptive Use by the Respondents



Source; Primary data

The above table shows the use of contraceptive methods used temporarily by the couples for less than 4 months prior to planning for pregnancy. The majority (45.25%) of respondents use condom as a barrier method of contraception, 29.5% report use of oral pills and 14.5% use copper T. There are respondents who use natural methods (10.75%), which indicate that a few respondents do not use specified birth control measures. A study done by Aleksandra. D (2015) reported that prolonged use of oral contraceptives decreased the risk of delayed conception and was associated with improved fecundity independent of other factors. The same author cited from other sources that use of intra-uterine devices had an increased risk of tubal infertility. In the present study, the use of contraceptives was obtained as a baseline data and was associated only with selected demographic data.

Table:2 Lifestyle Pattern of Respondents

Sl.No	Lifestyle Pattern	Male Percentage	Female Percentage
1	Smoking	26.2	0
2	Use of illegal drugs	0	0
3	Alcohol consumption	13.1	0
4	Exposure to radiation	0	0
5	Regular exercise	31.0	11.6
6	None	29.8	88.4
	Total	100.00	100.00

The above table depicts the lifestyle pattern of desirable couples. Smoking is reported among 26.2% of men. Both men and women don't report illegal drug use, 13.1% of men report alcohol intake, both men and women are not exposed to radiation or environmental pollutants, 31.0% of men do regular exercise and only 11.6% of women report regular exercise. No pattern is reported in 29.8% of men and 88.4% of women.

Table: 3 Past and Present history of illness among Respondents

Sl.No	Past & Present History of Illness	Male Percentage	Female Percentage
1	Past & Present surgical history	0	3.0
2	Diabetes	1.8	0
3	Hypertension	1.8	0.4
4	Heart diseases	0	0.4
5	Asthma	0.5	0
6	Arthritis	0	0
7	Thyroid disorders	0	3.0
8	Urinary infection	0	10.3
9	STI (Sexually transmitted Infection)	0	0
10	Intake of any drugs	0	0
11	Drug allergies	3.6	2.2
12	Others	92.3	75.0
	Total	100.00	100.00

The above table shows the past and present medical and surgical illnesses reported by couples with infertility. Only 3.0% of women have previous surgical histories including tonsillectomy and laparotomy. A very minimal proportion (1%) of men report having diabetes mellitus, 1% of men and 0.4% of women had high blood pressure or hypertension. There is no heart disease reported, 0.5% of men have asthma, urinary tract infections are more commonly reported (10.3%). Around 3.6% of men and 2.2% of women have drug allergies. As the above table gives a combination of past and present medical and surgical problems, there are no comprehensive study reports published to support the findings.

5. Discussion on the the overall perceptions of the Victims of infertility concerning Quality of Life of victims of infertility

On the whole, the findings of the study report that people living with infertility have low QOL scores, which are evident from the analysis. When comparing men and women, women are the most affected group. The FertiQoL includes mind and body (physical health), emotional health (psychological health status), social health (social and relational aspects), environmental aspects and tolerability to treatment aspects. The psychosocial determinants of life satisfaction among infertility were tested by Aleksandra (2015). The findings of the study reported that respondents who perceive more social support in general have better QOL scores across emotional, instrumental and support from institutions, support from family and friends, good self-esteem, lower hospital anxiety and lower depression scores. The robust factor, which causes high depression scores are due to a person's state of mind, which accepts one's own fertility condition. The study reported that if a person is able to accept his or her infertility status, it can have an influencing effect on the life satisfaction of individuals. This finding helps us to understand that women who have lower emotional QOL scores than men are not able to accept their infertile condition. So, the perception of respondents related to the overall satisfaction is decreased. The FertiQoL scores can have negative influences because of individual and familial characteristics and the stress of diagnosis of infertility and its treatment.

6. Theoretical Application

The study has the scope to assess the Role and Status of the victims of infertility hence, 'Sick Role Theory' propounded by Talcott Parsons is suitable to be applied. As pe the theory, illness cold be identified as temporary. The Socially defined role provides exemption from normal duties, the sick person has the right to be cared for and excused from the obligations but in the same time, they must desire to get well and seek appropriate medical help. The people with infertility are absolutely connected with the Parson's ideological context.

7. Sociological Implications

The study findings will provide guidelines for healthcare workers to plan interventions, as the findings reveal that women have lower QOL scores compared to men in the emotional domain. Similarly, men have lower QOL compared to women in the tolerability to treatment domain.
The findings will also bring in awareness among couples to understand how they can improve their QOL while undergoing infertility treatment. Non-Governmental Organisations and volunteers should be trained to counsel and support the interventions for improving life satisfaction and their QOL after diagnosis and during treatment of infertility.

8. Major findings

Most of the respondents (40.75%) earn between 20,001-30,000 INR Per month, 29.25% of respondents earn 30,001-40,000 INR per month. The majority of respondents (69.25%) are from urban settings ;55.25% belong to a nuclear family 39.5% live in a joint family. 45.25% of respondents use condom as a barrier method of contraception, 29.5% report use of oral pills; Smoking is reported among 26.2% of men. Both men and women don't report illegal drug use; men have asthma, urinary tract infections are more commonly reported (10.3%). Around 3.6% of men and 2.2% of women have drug allergies; the study reported that respondents who perceive more social support in general have better QOL scores across emotional, instrumental and support from institutions, support from family and friends, good self-esteem, lower hospital anxiety and lower depression scores.

9. SUMMARY AND CONCLUSION

People living with infertility face physical, psychological, social and environmental problems. They experience fear, anxiety, depression, stress and social stigma. They can approach healthcare providers to overcome these difficulties. Healthcare providers can provide the required positive attitude to instil hope. As per the objectives one of the sections has been found with Socio-economic data to collect information on 20 demographic variables to assess the socio-economic background of people living with infertility. Another section belongs to an internationally validated standardized tool to evaluate the QOL among people living with infertility. With regard to the living area, 39.01% of respondents are from urban areas within Chennai, 29.98% are from other metropolitan cities within India and 31.01% are from rural areas and villages (extension of remote areas). Men with lower QOL living with infertility have better

emotional, relational and social FertiQoL compared to women. While considering the tolerability to infertility treatment scores, women have better QOL scores.

This study clearly shows that factors contributing to infertility should be identified earlier. Interventions to resolve psycho-social and socio-cultural stress related to infertility are welcome, particularly for preventive services, which encourage couples to use the services and find out what prevents them from not utilising services. Determining the life satisfaction and QOL of life of people with infertility will help in careful planning and execution of reproductive health services in collaboration with couples, experts, NGOs and local communities. These types of services should only be used as complementary services and should not replace other community health provisions. Further studies can begin to define minimum standards for comprehensive infertility health services and can ascertain 'what is required' using appropriate research methodology. Further government services for infertility care in South India should be initiated, like what has been achieved in Goa, to support couples with infertility. This can enhance the QOL and life satisfaction among these victims.

10. RECOMMENDATIONS:

Based on the findings of the present study, the following recommendations are made:

1. Individuals with infertility are advised to go for regular health checkups and strictly follow the dos and don'ts recommended.
2. The study recommends the health sector to make health education mandatory in all the ART centres.
3. Development and promotion of the programme for fertility care in low-resource settings.
4. Support should be given to the global burden of diseases (GBD) group in the development of the envelope for infertility, which will determine the relative impact of infertility on society.
5. Social science research should be used to develop a better assessment of the QOL of people affected by infertility. The social burden of infertility in different regions should be evaluated in different cultural contexts.

Research Gap

Further, the studies may be conducted to provide interventions to cope up with the stress related to infertility and childlessness.

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