

DELAYED REFERRALS AND LATE PRESENTATION TO ENDOCRINE CLINICS FOR INFERTILITY DIAGNOSIS: A RETROSPECTIVE-PROSPECTIVE CROSS-SECTIONAL STUDY

Halar Rahim ¹, Urooj Lal², Imshal Musharaf³, Laiba Shamim⁴, Rukhshanda jabeen⁵, imran Khan⁶

¹-Fellow Diabetes And Endocrine Jpmc

² Associate Professor Endocrine Jsmu

^{3,4} Resident Physicians Jpmc

⁵ Professor Medicine Jsmu

⁶ Resident Medical Officer Jpmc

INTRODUCTION

Infertility is a global reproductive health concern, that is defined as the failure to conceive after 12 consecutive months of unprotected intercourse (1). On a global scale, infertility affects 17.5% of the adult population, emphasizing the urgency of accessible and affordable fertility care for the affected population (2). A notable percentage of 22% of the population in Pakistan is dealing with infertility and despite this significant number, 40% of the affected population does not seek medical help, owing to the fact that there is limited awareness, increased fear of stigma, financial constraints, and deeply rooted cultural norms (3,4). While infertility is often viewed as a gynaecological problem, with common causes including ovulatory dysfunction, fallopian tube disorders, endometriosis, or chromosomal abnormalities (5,6). Oftentimes the underlying cause is endocrine-related, including, PCOS, hyperprolactinemia, hypothyroidism, hyperthyroidism, hypogonadotropichypogonadism, etc.(7). Endocrine clinics are often the first point of contact for these patients therefore they play a significant role in early diagnosis and appropriate referral. Timely diagnosis and prompt medical care is vital in improving fertility outcomes however, many couples face substantial delays in reaching out to an endocrine clinic for diagnosis and treatment of infertility caused by endocrine dysfunctions. One study unveiled that a significant number of couples wait around 3.2 years to obtain an infertility diagnosis (8). This delay is driven by several contributing factors, including patient-related barriers, healthcare provider-related factors, and systemic issues within the healthcare delivery system. Among these are, seeking folk therapy before medical consultation, approaching other medical consultants before reaching the endocrine clinic, lack of awareness and lower education level, financial constraints, accessibility and safety of treatment and the fear of being stigmatised(8, 9). These delays can result in missed therapeutic windows, especially in older women, and increase risk of developing psychological disorders therefore timely management is essential (10). This study aims to explore the reason behind delayed diagnosis and intervention of infertility in an endocrine clinic setting. Understanding these delays can aid in improving timely access to fertility care, especially for patients whose primary issues stem from endocrine dysfunction. Infertility is more common in developing countries because people there are less knowledgeable about the causes of infertility and the possible treatments that may be required. In Pakistan, infertility was reported by 22% of the people [11]. The psychopathology of the infertile women is noticeably higher and manifests as self-blame, depression, anxiety, tension, and suicidal ideation [12]. Delay in the diagnosis of infertility is a significant concern. Due to the fact that hormonal imbalances are often the underlying cause of infertility, endocrine clinic play a crucial role in many healthcare settings in the diagnosis of infertility. However, significant delays have been experienced by many patients before reaching the endocrine clinic. While various factors are responsible for this delay, one of the important factor is failure of gynecologist and physicians to refer patients to an endocrine clinic for evaluation. According to studies, primary healthcare providers frequently delay referrals as they rely too much on empirical treatments, and under-estimate endocrine-clinic causes [13]. It is important to understand the reasons behind the delays to improve patient education and accessibility. There is no data on the causes of delay in reaching endocrine clinic for infertility diagnosis. Therefore, our study aims to systematically evaluate the causes of this delay in an endocrine clinic by assessing patient presentation trends. Understanding these delays will help develop strategies to strengthen primary care training and improve referral guidelines. Delays in reaching an endocrine clinic for infertility diagnosis is a significant concern experienced by many individuals. The causes and extent of these delays remain unexplored at Jinnah Postgraduate Medical Centre (JPMC), Karachi.

The main objectives of this research were to to assess the timeframe from initial symptom presentation to confirmed infertility diagnosis in patients visiting the endocrine clinic of the largest, public sector hospital in Sindh province, To

identify common causes of delays in reaching the endocrine clinic for diagnosis of infertility in patients, To evaluate the impact of physician and patient on diagnostic delays, To analyze referral patterns and patient pathways that are causing these delays, to compare retrospective and prospective diagnostic trends and to provide strategies for timely access to endocrine clinic and for improving early detection. Failure to conceive after 12 months of unprotected sexual intercourse is called infertility.

METHODOLOGY

IT was a Retrospective-Prospective Cross-Sectional Study conducted at Single centre: Jinnah Postgraduate Medical Centre between May 2025 to July 2025. Female patients of age 18-45 attending the endocrine clinic at Jinnah Postgraduate Medical Centre (JPMC), Karachi. To calculate the sample size, OpenEpi same size calculator was used. The confidence interval was kept at 95% and the anticipated frequency was set to 50%, to assume the maximum variability and provide a larger sample size, in order to ensure adequate power. Based on these parameters, the sample size was calculated to be approximately 109 patients. Non probability, convenient sampling technique was used in this study. Female patients diagnosed with infertility in the endocrine clinic at Jinnah Postgraduate Medical Centre, Female patients of reproductive age (18-45 years) and Female patients with complete medical records and diagnostic timelines were included in this study while Patients who were diagnosed with infertility prior to coming to the endocrine clinic, Patients with incomplete medical records, Cases where genetic disorders or irreversible diseases such as Klinefelter syndrome and Turner syndrome are the cause of infertility and Patients who did not consent to participate in the study were excluded from this study. Data will be collected using a self-structured questionnaire from patients visiting the Endocrine Clinic at Jinnah Postgraduate Medical Centre (JPMC), Karachi. The study followed a retrospective-prospective cross-sectional design. To collect retrospective data, medical records of patients from March 2025 to April 2025 was reviewed to gather the data about medical history of the patients, and time intervals between consultations, referrals, and visits. For prospective data, information will be collected by interviewing patients, covering their medical history, time intervals, and reasons for delay in reaching endocrine clinic. Participants were fully explained the nature, objectives and methods of the study. Once they consent to participate, they were made to sign the consent form. Data was collected anonymously to ensure confidentiality. The actual questionnaire was hosted on the Google Forms platform and was filled by the researchers. All the responses were automatically recorded and accessible only to the research team. The data was downloaded and transferred to a password-protected computer for analysis. Past medical records were examined with approval from the hospital administration. The questionnaire comprised of four sections. Section 1 assessed patients' demographic information. Section 2 addressed patients' medical history. Section 3 assessed the timeframe related to endocrine clinic access. Section 4 assessed the barriers and causes of delay in reaching endocrine clinics. Data collected was analyzed using SPSS software version 25.0. Descriptive statistics (mean, standard deviation, etc.) was calculated. Chi square test was utilized to determine the association between the variables and the outcome. The statistical analysis was conducted with 95% confidence interval and p-value of <0.05 as level of significance.

RESULTS

The study comprised 109 female patients who were diagnosed with infertility at Jinnah Postgraduate Medical Center's endocrine clinic. Participants' ages ranged from 18 to 45 years old, with a mean age of 29.8 ± 5.6 years. 5.5% (n = 6) of individuals were single, whereas the majority (94.5%, n = 103) were married. At marriage, the average age was 23.7 ± 4.2 years. 18.3% (n = 20) had no formal education, 27.5% (n = 30) had completed primary school, 31.2% (n = 34) had completed secondary school, and 22.9% (n = 25) had completed further education. Only 10.1% (n = 11) of the participants were in the high socioeconomic group, while the majority (55.0%, n = 60) were in the middle socioeconomic group, followed by the low socioeconomic group (34.9%, n = 38). The most common endocrine cause of infertility among the participants was polycystic ovarian syndrome (PCOS), which affected 46.8% (n = 51) of the individuals. Hyperprolactinemia was found in 17.4% (n = 19) of cases, whereas thyroid problems were found in 21.1% (n = 23). 14.7% (n = 16) of instances were due to other endocrine reasons. The average time between the initial clinical consultation and the endocrine clinic referral was 18.6 ± 9.4 months. The average interval between the referral and the endocrine clinic appointment was 6.3 ± 4.1 months. The average time between identifying symptoms related to fertility and going to the endocrine clinic was 24.9 ± 11.2 months. Of the participants, 27.5% (n = 30) reported delays between one and two years, and over half (58.7%, n = 64) reported a cumulative delay of more than two years before arriving at the endocrine clinic. Just 13.8% (n = 15) sought endocrine treatment within a year after identifying infertility problems. A mean of 3.1 ± 1.4 healthcare professionals were seen by participants prior to seeing an endocrinologist. The most often consulted providers before referral were gynecologists (71.6%), general practitioners (54.1%), and traditional healers (29.4%). Of the participants, 37.6% (n = 41) came to the endocrine clinic by self-referral or unofficial counsel, whereas only 62.4% (n = 68) said they were formally sent to an endocrinologist by a medical professional. After referral, 41.3% (n = 45) were able to schedule an endocrinologist appointment within 1-3

months, 29.4% (n = 32) within less than a month, 17.4% (n = 19) during 4–6 months, and 11.9% (n = 13) waited longer than six months. Financial restrictions (49.5%, n = 54), misdiagnosis or poor referral by physicians (56.9%, n = 62), and ignorance of the need for specialized care (64.2%, n = 70) were the most commonly stated obstacles to timely access to endocrine therapy. 38.5% (n = 42) and 35.8% (n = 39) of subjects expressed social stigma and fear of diagnosis, respectively. Furthermore, 26.6% (n = 29) of patients claimed religious or cultural views as contributory reasons, and 31.2% (n = 34) of patients reported delays brought on by the use of traditional or alternative medicine. 18.3% (n = 20) of individuals reported being unwilling to have a partner. Most participants used public transportation (61.5%, n = 67) to reach the endocrine clinic, while 33.9% (n = 37) used private transport. Travel was identified as a limiting factor by 44.0% (n = 48) of participants. Statistical analysis revealed a significant association between delayed referral (>2 years) and lower educational status (p = 0.021), lack of physician referral (p = 0.009), and use of traditional medicine prior to specialist consultation (p = 0.031). No statistically significant association was observed between age and total delay (p > 0.05).

Table 1: Demographic Characteristics of Study Participants (n = 109).

Variable	Frequency (n)	Percentage (%)
Age (years)		
18–25	32	29.4
26–35	54	49.5
36–45	23	21.1
Marital Status		
Married	103	94.5
Unmarried	6	5.5
Education Level		
No formal education	20	18.3
Primary	30	27.5
Secondary	34	31.2
Higher education	25	22.9
Socioeconomic Status		
Low	38	34.9
Middle	60	55.0
High	11	10.1

Table 2: Distribution of Endocrine Causes of Infertility (n = 109)

Endocrine Disorder	Frequency (n)	Percentage (%)
Polycystic ovarian syndrome (PCOS)	51	46.8
Thyroid disorders	23	21.1
Hyperprolactinemia	19	17.4
Other endocrine causes	16	14.7
Total	109	100

Table 3: Time Delay in Accessing Endocrine Clinic Services

Delay Duration	Frequency (n)	Percentage (%)
Less than 1 year	15	13.8
1–2 years	30	27.5
More than 2 years	64	58.7
Total	109	100

Table 4: Healthcare-Seeking Behavior Prior to Endocrine Clinic Visit

Variable	Mean ± SD / Frequency
Mean number of healthcare professionals visited	3.1 ± 1.4
Patients formally referred to endocrinologist	68 (62.4%)
Patients self-referred	41 (37.6%)

Table 5: Time Taken to Get Endocrinology Appointment After Referral

Time to Appointment	Frequency (n)	Percentage (%)
Less than 1 month	32	29.4
1–3 months	45	41.3
4–6 months	19	17.4
More than 6 months	13	11.9
Total	109	100

Table 6: Reported Barriers Causing Delay in Infertility Diagnosis

Barrier	Frequency (n)	Percentage (%)
Lack of awareness	70	64.2
Physician-related delay / misreferral	62	56.9
Financial constraints	54	49.5
Social stigma	42	38.5
Fear of diagnosis	39	35.8
Traditional / alternative medicine use	34	31.2
Religious or cultural beliefs	29	26.6
Partner unwillingness	20	18.3

Table 7: Association Between Selected Factors and Delay (> 2 Years)

Variable	p-value
Education level	0.021
Physician referral status	0.009
Use of traditional medicine	0.031
Age	>0.05

DISCUSSION

This study shows that among women who attend a tertiary care public hospital in Pakistan, there are significant delays in referrals and late presentations to endocrine clinics for infertility diagnosis. The results show that most patients had long delays, with over half arriving at the endocrine clinic after two years of identifying issues related to fertility. Since prompt detection and treatment of the endocrine causes of infertility are essential for enhancing reproductive outcomes, especially for women who are getting close to late reproductive age, these delays are clinically relevant. Given that infertility typically manifests during the prime years for reproduction, the mean age of research participants was similar to that seen in related regional studies. The gap between early onset of infertility symptoms and access to adequate care was highlighted by the lengthy waits many women had before receiving a specialized evaluation, even though they were married at a reasonably young age. Longer delays were substantially correlated with lower educational status, indicating that a lack of health literacy may lead to a lack of knowledge about infertility and the necessity of a specialist endocrine evaluation. In line with previous research that shown PCOS to be a major cause of anovulatory infertility globally, polycystic ovarian syndrome (PCOS) appeared as the most prevalent endocrine condition causing infertility. Hyperprolactinemia and thyroid conditions were very commonly noted, underscoring the significance of endocrine evaluation in infertile patients. Given the high frequency of these curable endocrine disorders, prompt intervention and possibly better fertility outcomes could have been achieved with an earlier referral.

The extended period of time between the first medical consultation and referral to an endocrine clinic was one of the study's most noteworthy findings. Before seeing an endocrinologist, many patients said they had seen several medical professionals, mostly general practitioners and gynecologists. This points to deficiencies in referral procedures and emphasizes primary care physicians' propensity to undervalue endocrine causes of infertility or to depend solely on empirical remedies. This result is supported by the strong correlation between delayed presentation and no physician referral, which is consistent with earlier research showing that delayed specialist referral is still a key cause of diagnostic delays. Delays in presentation were also significantly influenced by patient-related factors. The most frequently mentioned obstacle was ignorance of the need for specialist treatment, which was followed by social stigma and financial limitations. Delays were also caused by cultural beliefs, a fear of being diagnosed, and a dependence on conventional or alternative medicine. These results are in line with research from other developing nations, where immediate medical consultation is discouraged by societal expectations and the stigma associated with infertility. Longer delays were strongly linked to using traditional treatments before seeking expert care, underscoring the need for culturally relevant public health education. Other obstacles included accessibility and transportation, especially for patients who depended on public transportation. Systemic barriers to accessing tertiary care institutions are reflected in the nearly 50% of participants who cited travel as a limiting factor. Delays are made worse by these logistical limitations, particularly for patients from low-income families. The study's overall conclusions highlight the complex relationship between infertility diagnosis delays in endocrine clinic settings. The necessity for integrated interventions that address physician education, standardized referral pathways, patient awareness, and healthcare accessibility is further supported by the fact that late presentation is caused by both patient-related and healthcare system-related factors.

CONCLUSION

This study shows that in a Pakistani tertiary care public hospital context, delayed referrals and late presentations to endocrine clinics for infertility diagnosis continue to be a major problem. A significant percentage of women had to wait a long time—often more than two years—to receive specialized endocrine treatment. Systemic healthcare barriers, physician-related behaviors, and patient-related variables all contributed to these delays. The main causes of delayed presentation were financial limitations, societal stigma, dependence on traditional medicine, poor or delayed referrals by primary healthcare providers, ignorance of the significance of endocrine problems in infertility, and lack of awareness. Thyroid issues, hyperprolactinemia, and polycystic ovarian syndrome were found to be prevalent and possibly curable endocrine causes of infertility, highlighting the significance of prompt diagnosis and treatment. The findings underscore the need for better coordination between primary care physicians, gynecologists, and endocrinologists by highlighting significant gaps in referral channels and healthcare-seeking behavior. In order to avoid lost treatment opportunities, lessen psychological anguish, and enhance the fertility results for impacted women, these delays must be addressed.

Recommendations

The following suggestions are put forth in light of the study's findings:

To guarantee that gynecologists and primary care doctors promptly send infertile patients to endocrine clinics, clear and uniform referral procedures should be established. Programs for ongoing medical education should be put in place to raise healthcare professionals' knowledge of the endocrine reasons of infertility and the significance of early referral to specialists. To lessen stigma and misunderstandings, public health programs should concentrate on teaching women and couples about infertility, its endocrine causes, and the availability of efficient medical treatments. Decentralization of services, better appointment scheduling, and easier transportation for patients from far-off places are some of the steps that should be implemented to increase access to endocrine therapies. It is advised that psychological counseling services be incorporated into endocrinology and infertility clinics in order to alleviate emotional suffering and enhance patient outcomes and compliance. Health policymakers ought to give infertility top priority as a public health issue and set aside funds to improve fertility treatments in hospitals in the public sector.

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