



PERCEPTION AND ATTITUDE OF PATIENTS REGARDING POLYCYSTIC OVARIAN SYNDROME (PCOS) IN TERTIARY CARE HOSPITALS OF PAKISTAN - A SURVEY BASED STUDY

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ABSTRACT

Polycystic ovarian syndrome is the most common endocrinal disorder in women all over the world. In addition to infertility the rates of co morbidities are also significantly higher in women with PCOS. It has been associated with obesity and other metabolic abnormalities as well however the understanding of PCOS among both patients and community at large remains imprecise. A quantitative cross sectional survey was carried out to evaluate the perception of patients with polycystic ovarian syndrome PCOS in Pakistan. This survey was conducted over a period of 8 months. The data was analyzed by SPSS and employed descriptive statistics and chi square tests. A total of 270 patients were available for their clinical data to be recorded. In terms of demographics, the survey revealed that majority of the patients (37%) were in adult age group and a considerable number of patients (25.9%) were also seen in middle age groups and teenage groups (22.2%), whereas geriatrics were observed to be the least in number (14.8%). In terms of BMI, majority were observed to be obese (51.8%) and extremely obese (22.2%). Finally, the patients were asked regarding their understanding about the disease, majority of patients (55.6%) answered negatively. The patients of polycystic ovarian syndrome are mostly young and the comprehension and awareness regarding the disease among the patients is generally found to be deficient. Equipping them with knowledge may lead to improved quality of life and a pharmacist can play a role in the said regard.

Key Words:- Perception, Attitude, Patients, Polycystic ovarian syndrome, PCOS, Tertiary care setting, Pakistan.

INTRODUCTION

Polycystic ovary syndrome has been considered to be the most common cause of oligoovulatory infertility (Hull MG, 1987) and these patients are also at higher risk for developing dysfunctional uterine bleeding and endometrial carcinoma, and a number of metabolic disorders, including insulin resistance, diabetes mellitus, hypertension, dyslipidemia, and cardiovascular disease (Knochenhauer ES, 1998). The terminology polycystic

syndrome refers to the presence of small, benign and painless cysts in the ovaries, which are clinically manifested by a faction of symptoms and changes in hormonal levels. Although the exact cause of PCOS is unknown, it is contemplated that the hormonal imbalance is the major underlying reason for it. It has also been called “ovarian androgen excess” (Ricardo A, 2004), as the ovaries begin producing androgen in increased amounts in presence of PCOS. PCOS is difficult to diagnose, as it is often a diagnosis that is reached by exclusion of other medical conditions that cause irregular menstrual cycles and androgen excess (Zahida B, 2010).

The polycystic ovary syndrome was first reported in 1935 (Stein IF,1935) and since then number of studies

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have been conducted on the prevalence of the disease however these studies are greatly dependant on the selected criteria as is the case with all multi factorial complex diseases . Polycystic ovary syndrome is the most common endocrine abnormality in women of reproductive age, and its prevalence is estimated to be 4–8% in studies performed in Greece, Spain and the USA (Azziz R, 2004) The prevalence of PCOS is increasing the world over and is showing a galloping increase in parallel with the rising prevalence of type 2 diabetes mellitus (T2DM). (Ashraf Ganie M, 2011). The prevalence is found to be significantly high in women in Pakistan and various studies have determined the frequency of PCOS to be 20-33% in general population (Polson DW 1988) however the highest reported prevalence of PCOS was 52% among South Asian immigrants in Britian (Rodin DA, 2002).

Treatment of PCOS is complex as it requires multidimensional therapeutic approach in order to counter the co morbidities associated with it. Other then the physiological co morbidities, several studies have reported women who have PCOS are more prone to depression, anxiety, low self-esteem, negative body image, and psychosexual dysfunction (Deeks A 2010), which adds complexities to therapeutic management, therefore life style alteration is considered to be the first line in the management of PCOS. Evidence shows that lifestyle change with as little as 5–10% weight loss has significant clinical benefits improving psychological outcomes (Galletly C, 1996). At the moment there are no clinical guidelines that can completely reverse all the clinical manifestations of PCOS.

Some of the components of PCOS are known to be profoundly stressful, yet effective and systematic efforts to characterize the subjective awareness of this disorder have only recently been developed (Cronin L, 1998). As these laudable education efforts gain momentum, however, the current state of patient comfort with their "level of awareness" regarding PCOS, where their facts come from, and how they feel about their diagnosis are imprecisely characterized (Scott Sills E, 2001).

This study was conducted to evaluate the perception of patients of polycystic ovaries regarding this disease and a contemporary awareness regarding it. Also the effect and the consequences of the co morbidities and the factors associated with it were appraised.

METHODS

A quantitative cross sectional survey was selected with the objective of recording the patient perception of polycystic ovarian syndrome PCOS. The target population consisted of patients diagnosed with polycystic ovarian syndrome in Pakistan. The inclusion and exclusion criteria were set as all patients who were diagnosed with polycystic ovarian syndrome PCOS were included and others were excluded from the study. Probability sampling technique was used on the target group. A questionnaire was designed to record the information of the patients. Prior to data collection, it was validated by a team of experts to check its feasibility and suitability. The patients were explained the data collection process and its objectives and a written consent form was obtained from patients as well as an ethics committee approval from institution were also sought. The survey was carried out in Karachi, Pakistan for 8 months i.e. March 2013 to October 2013. A data of 270 patients was collected analyzed using SPSS v 20 (Statistical package for social sciences version 20). The chi square test of goodness of fit and association was used to analyze the data statistically. The data expressed as number of patients (N), percentage (%), standard deviation (SD) and significant P values (*P value*). Statistical significance was accepted at P values <0.05.

RESULTS

A total of 270 patients were available for their clinical data to be recorded. In terms of demographics, the survey revealed that majority of the patients (N = 100, 37%) lied in adult age group of 21 to 30 years and a considerable number of patients (N = 70, 25.9%) were also seen in middle age groups and teenage groups (N = 60, 22.2%), geriatrics were observed to be the least in number (N = 40, 14.8%). (SD 1.0).

Table 1. Summary of demographic results

S.No	Demographic Profile	N	%	SD	P-value
1	Age of Patients			0.4	<0.05
	11 to 20 years	60	22.2%		
	21 to 30 years	100	37%		
	31 to 40 years	70	35.9%		
	Above 40 years	40	14.8%		
	Total	270	100%		
2	Body mass index			0.9	<0.01
	Normal	20	7.4%		

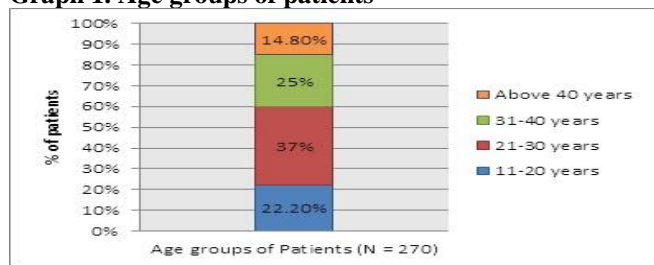
	Overweight	50	18.5%		
	Obese	140	51.9%		
	Extremely obese	60	22.2%		
	Total	270	100%		
3	Age of diagnosis			0.9	<0.01
	Adolescents	130	48.1%		
	Adult	80	29.6%		
	Middle Aged	40	14.8%		
	Geriatrics	20	7.4%		
	Total	270	100%		
4	Family History			0.86	<0.05
	Menstrual Problems	110	40.7%		
	Obesity	100	37%		
	PCO	50	18.5%		
	Hormonal changes	10	3.7%		
	Total	270	100%		

Further to this, they patients were asked about the complications faced by them and majority mentioned obesity (N = 140, 51.9%) and infertility (N = 90, 33.3%). However, some cases of miscarriages (N = 30, 11.1%) and hirsutism (N = 10, 3.7%) was also reported. (SD 1.3).

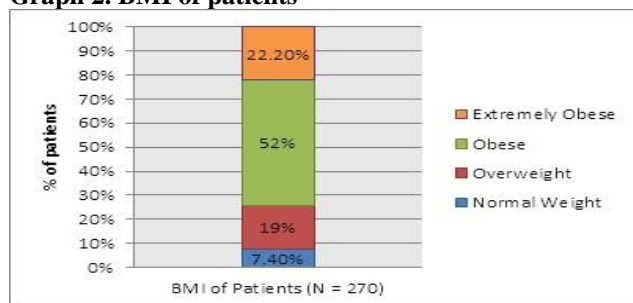
Table 2. Summary of patients' perception

S.No	Perceptions	N	%	SD	P-value
1	Complications of disease			1.3	<0.05
	Obesity	140	51.1%		
	Miscarriage	30	11.9%		
	Hirsutism	10	3.7%		
	Infertility	90	33.3%		
	Total	270	100%		
2	Impact of the disease			0.44	<0.05
	Yes	200	74.1%		
	No	70	25.9%		
	Total	270	100%		
3	Understanding of disease			0.5	>0.05
	Yes	120	55.6%		
	Do not know	150	44.4%		
	Total	270	100%		
4	Association				<0.01
	Age with understanding of the disease				

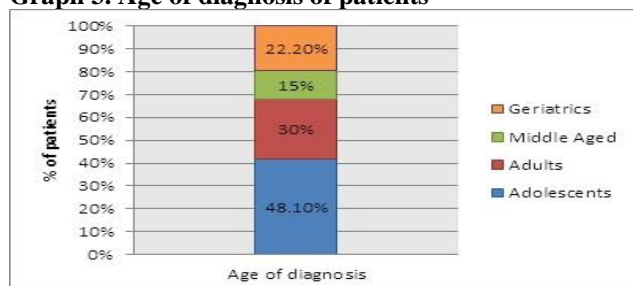
Graph 1. Age groups of patients



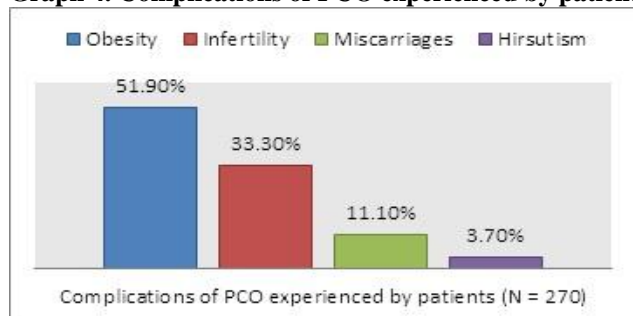
With regards to BMI of the patients majority fell in the category of obese patients majority were observed to be obese (N = 140, 51.8%) and extremely obese (N = 60, 22.2%). Few were observed to be overweight (N= 50, 18.5%). Two patients (N = 20, 7.4%) had normal weight. (SD 0.4)

Graph 2. BMI of patients

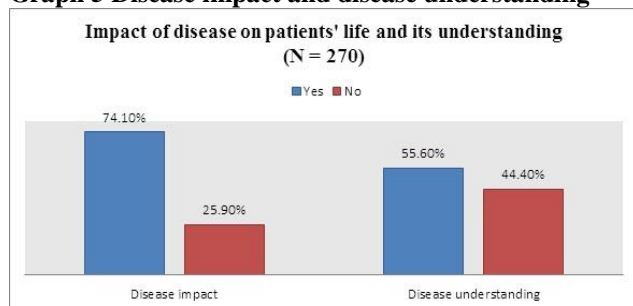
Further to this, the age at which the PCOS was first diagnosed was also recorded. It was found that the highest number of case reported in young age i.e. adolescents (N = 130, 48.1%) and adults (N = 80, 29.6%). However, middle aged (14.8%) and geriatrics (7.4%) were seen less associated in this case. (SD 0.9)

Graph 3. Age of diagnosis of patients

The demographic profile is also summarized in table 1. In addition, the patients were asked about the family history and majority reported menstrual problems (N = 110, 40.7%) and obesity (N = 10-, 37%). Few mentioned PCO (N = 50, 18.5%) in their family (SD 0.86).

Graph 4. Complications of PCO experienced by patients

In addition, the patients were asked if the disease has impacted their life and bulk of patient (N = 200, 74%) responded by acknowledging the impact the disease had in their life while the rest (N = 70, 25.9%) did not feel any impact of the PCO in their life (SD 0.44). Finally, the patients were asked if they understand the disease. Majority of patients (N = 150, 55.6%) answered negatively while the rest (N = 120, 44.4%) had information about the disease (SD 0.5).

Graph 5 Disease impact and disease understanding

The associations of demographics with perception was tested with chi square test and it was observed that the age of patients was associated with their understanding of the disease (P- value <0.05). Table 2. summarized the results of the perceptions of the patients.

DISCUSSION

Polycystic ovarian syndrome is an endocrinal disorder which is one of the causes of female infertility (Darion *et al.*, 2011) and has the potential for serious long term health effects (Kelly CJ, 2000). A study carried out in tertiary care settings in Pakistan on the aforementioned

issue and found out that the patients suffering from PCOS were majorly found in the age range of 15-30 years although the geriatric population also was found to be suffering from PCOS the rate of occurrence was lower. This evaluation was indicative of the need for diagnosis and work up in not only the adults but also in the younger

population who are exhibiting risk factors suggestive of the disease, with the growing prevalence even in the pre adolescent age group. The need to increase the awareness and knowledge in the young females was one of the focal point of the study as it was observed that probability of development of PCOS is greatest at adolescence and young age as compared to older age groups.

It has been established that 35%–65% of PCOS patients are obese (Al-Azemi, 2004), and is the foremost issue in the treatment of fertility in women suffering from PCOS, the presence of significant majority of obese women in this study highlighted probability of increased risk and presence of PCOS in patients with a high BMI.

There is strong evidence that PCOS is a genetic disease supported by familial clustering of cases (Diamanti-Kandarakis E, 2006). Although the genetic penetration is high, the expression is found to be variable. In the symptoms of PCOS, the clinical manifestations are highly determined by factors such as obesity and abnormal menstrual cycles. The patients tend to exhibit either both or one of these symptoms frequently. The hormonal imbalance underlying PCOS also leads to other clinical manifestations which cannot be correlated to the hereditary aspect these include hirsutism, infertility and miscarriages that are commonly observed in patients.

Specifically the most negative emotion identified by patients with PCOS were the psychological effects of depression and anxiety felt by these females as a result of the co morbidities and physical changes experienced by them. This in turn led to the focal issue of the study regarding the knowledge and the perception as conceived by the patients which was significantly low. This data confirms the lack of education and knowledge among the patients regarding the disease and hence the apprehensions can be associated to this poor conception by the patients of the disease and its associated co morbidities.

REFERENCES

- Al-Azemi M, Omu FE, Omu AE. The effect of obesity on the outcome of infertility management in women with polycystic ovary syndrome. *Archives of gynecology and obstetrics*, 270, 2004, 205–210
- Ashraf Ganie M and Sanjay K. Polycystic ovary syndrome – A metabolic malady, the mother of all lifestyle disorders in women – Can Indian health budget tackle it in future? *Indian J Endocrinol Metab*, 15(4), 2011, 239-241.
- Azziz R, Woods KS, Reyna R, Key TJ, Knochenhauer ES, Yildiz BO. The prevalence and features of the polycystic ovary syndrome in an unselected population. *J Clin Endocrinol Metab*, 89, 2004, 2745–2749.
- Cronin L, Guyatt G, Griffith L *et al*. Development of a health related quality of life questionnaire for women with polycystic ovary syndrome (PCOS). *J Clin Endocrinol Metab*, 83, 1998, 1976-1987.
- Deeks A, Gibson-Helm M, Teede H. Anxiety and depression in polycystic ovary syndrome (PCOS): A comprehensive investigation. *Fertil Steril*, 93, 2010, 2421–3.
- Diamanti-Kandarakis E, Kandarakis H, Legro RS. The role of genes and environment in the etiology of PCOS. *Endocrine*, 30 (1), 2006, 19–26.
- Draion MB and Paige EP. Managing the complications of polycystic ovarian syndrome. [internet]. *AOA Health Watch*, 2011.

The patients failed to develop an understanding of the disease which again refers to the scarcity of health care professionals in Pakistan such as pharmacists who can serve as information experts. The study incorporated just 270 patients of PCO as many patients did not consented to participate keeping in view the sensitive nature of the disease and social factors that influence in the consent and disclosure of the disease. The authors express this factor as a limitation in the study. Nonetheless, it can be termed as a foundation study and further digging is recommended in the domain to have a better understanding of what patients perceive about polycystic ovarian syndrome.

CONCLUSION

The patients of polycystic ovarian syndrome are mostly young and do not have understanding of the disease to the extent they should. A disease awareness campaign or an educational intervention by a health care professional such as a pharmacist is the need of the hour.

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CONFLICT OF INTEREST

The authors declare no conflict of interests exists.

AUTHOR'S CONTRIBUTION

All author contributed equally in all aspects of the study.

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- Galletly C, Clark A, Tomlinson L, Blaney F. A group program for obese, infertile women: Weight loss and improved psychological health. *J Psychosom Obstet Gynaecol*, 17, 1996, 125–8.
- Hull MG. Epidemiology of infertility and polycystic ovarian disease: endocrinological and demographic studies. *Gynecol Endocrinol*, 1, 1987, 235–245.
- Kelly CJ, Connell JM, Cameron IT, Gould GW, Lyell H. The long term health consequences of polycystic ovary syndrome. *Br J Obstet Gynaecol*, 107, 2000, 1327-38
- Knochenhauer ES, Key TJ, Kahsar-Miller M, Waggoner W, Boots LR and Azziz R. Prevalence of the Polycystic Ovary Syndrome in Unselected Black and White Women of the Southeastern United States: A Prospective Study. *The Journal of Clinical Endocrinology & Metabolism*, 83, 1998.
- Polson DW, Adams J, Wadsworth J, Franks S. Polycystic Ovaries—a common finding in normal women. *Lancet*, 1988, 870-872.
- Ricardo AAD and David E. Polycystic Ovary Syndrome. *The Journal of Clinical Endocrinology & Metabolism*, 89(90), 2004.
- Rodin DA, Bano G, Balnd JM, Taylor K, Nussey SS. Polycystic ovaries and associated metabolic abnormalities in Indian subcontinent Asian women. *Clin Endocrinol*, 49, 2002, 91-2.
- Scott Sills E, Mark P, Michael JT, Carolyn RK, Marc GG, Glenn LS. Diagnostic and treatment characteristics of polycystic ovary syndrome: descriptive measurements of patient perception and awareness from 657 confidential self-reports. *BMC Women's Health*, 1, 2001, 3.
- Stein IF, Leventhal ML. Amenorrhea associated with bilateral polycystic ovaries. *Am J Obstet Gynecol*, 29, 1935, 181–191.
- Zahida B, Majidah KSP. Prevalence of PCOs in infertile patients. *Medical Channel*, 16(3), 2010.