A STUDY OF THE CORRELATION BETWEEN POLYCYSTIC OVARIAN SYNDROME AND MENTAL HEALTH: CLOSER LOOK AT THE EFFECT OF AGE, ENVIRONMENT AND COPING METHOD

Dissertation submitted in partial fulfilment of the requirements of the Bachelor's Degree in Zoology

By

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Submitted to

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DECLARATION

The current study “A study of the correlation between Polycystic Ovarian Syndrome and mental health: Closer look at the effect of age, environment and coping method” has been carried out under supervision of Dr. Jyothi Rani, Professor of Zoology, St. Francis College for Women. I hereby declare that the present study that has been carried out by me, Khadijah Saleem Ahmed, from March 2020 to May 2021, is original and no part of it has been carried out prior to this date.

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CONTENTS

LIST OF TABLES

LIST OF FIGURES

LIST OF ABBREVIATIONS

PCOS - polycystic ovarian syndrome

BPD - bipolar disorder

BED - binge-eating disorder

OCD - obsessive compulsive disorder

ADHD - attention deficit hyperactivity disorder

EDNOS - eating disorder not otherwise specified

ED - eating disorder

LH - luteinizing hormone

FSH - follicle--stimulating hormone

ABSTRACT

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PCOS, or Polycystic Ovarian Syndrome, is a common disorder affecting 15-20% of people with ovaries. While mental health illnesses affect 1 in 7 people globally, they are more common in a few countries like India and England. Hence, the two issues overlap. PCOS can cause or enhance psychological effects, resulting in mental health problems. A survey of 357 participants was taken to assess how age, social environment and coping methods or mechanisms affected people with PCOS and their mental health. The data revealed that PCOS can greatly impact mental health: 98.9% of people with PCOS face at least one mental health issue. Increasing age does not make it easier to manage PCOS. Also, the socio-cultural environment can stop people with PCOS from talking about PCOS or their mental health due to stigma and other possible consequences. At least 5% of people with PCOS are unable to manage PCOS; most rely on a combination of methods, none of which is a universal solution for everyone with the syndrome. Almost 95% of the participants strongly believe that education from a younger age can help people with PCOS manage their mental health in a better manner. Research in this area is unfortunately still scant and requires more in-depth, long-term research.

CHAPTER 1
INTRODUCTION

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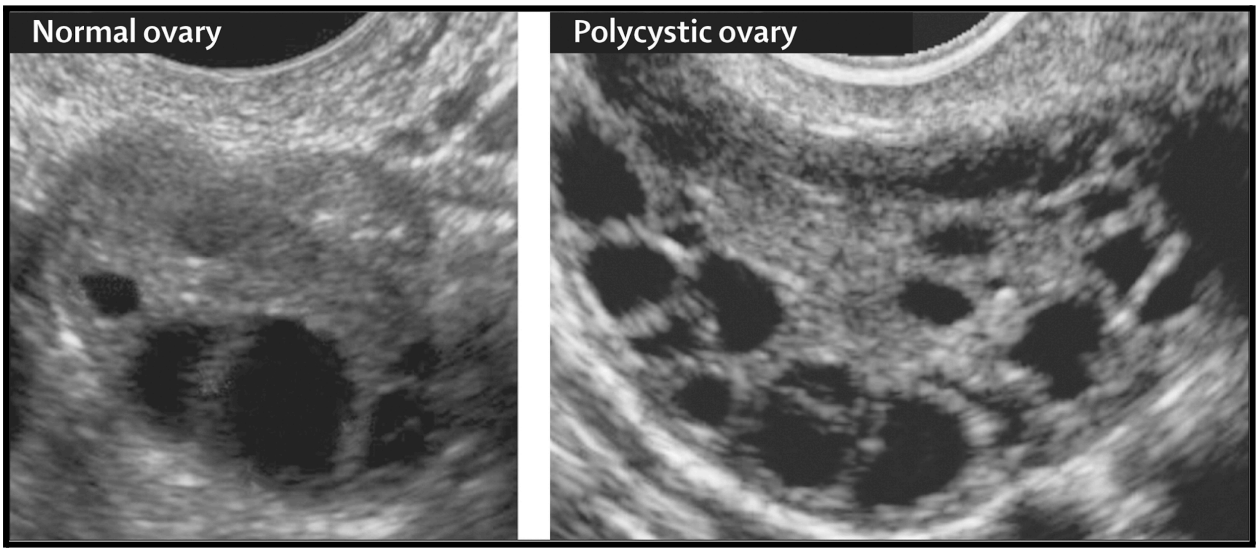
Polycystic Ovarian Syndrome, or PCOS, otherwise called Polycystic Ovarian Disorder (PCOD) or Stein-Leventhal syndrome, is an endocrine disorder caused due to imbalanced hormones. Due to a higher LH/FSH ratio, the production levels of androgens are also higher. Symptoms of PCOS vary, and may include acne and hirsutism as a result of high androgen levels. It is also closely linked to weight gain, insulin resistance, diabetes and infertility. PCOS acts only as a factor in all of these; it is not necessary for a person with PCOS to experience all of these.

Typically, the diagnosis of PCOS requires a person to have 2 of 3 conditions:

1) Irregularity or absence of periods
2) Increased levels of androgen
3) Multiple cysts on one or both ovaries (leading to the word 'polycystic')

Figure 1.1

Normal ovary vs polycystic ovary on ultrasound (Norman et al., 2007)



On the surface, it seems that the diagnosis should not be too difficult, especially as the medical field has advanced greatly. The first of the three aforementioned conditions is naturally quite easy to observe for any menstruator, after all. However, during the diagnosis itself, the method of diagnosis is largely one of exclusion - that is, PCOS is given as a diagnosis only when other diagnoses do not seem to be a match. It thus varies with the patient's presenting symptoms too, as an extra symptom may work against the other possible diagnosis. To give an instance, only a third (33.3%) of adults with only amenorrhea were diagnosed with PCOS, but if amenorrhea is coupled with symptoms like hirsutism, then the diagnosis rate jumps to 70% or more (Rathour & Singh, 2020). Thus, it is essential that one understands how the variation in symptoms affects diagnosis.

Figure 1.2

Hirsutism (Conquer PCOS, 2020)

While some people find out at an early age that they have PCOS, others find out much later, such as when they face issues with getting pregnant. A study conducted on 1385 people with PCOS showed that 170 women went to over 5 doctors before being diagnosed, suggesting the difficulty in receiving a diagnosis at the right time (Gibson-Helm et al., 2016). The same study further showed that a third of the people with PCOS, meaning nearly 700 people,

required over two years and three or more health professionals to be finally diagnosed with PCOS. The gap in suffering from PCOS and its diagnosis can be a result of stigma, especially in countries like India. However, around the world, the reason for this could be merely lack of access to proper healthcare, such as in the US. Fortunately, healthcare has improved worldwide, and so has education, resulting in the diagnosis rate increasing from 6-15% till around 2010 (Fauser et al., 2011; Kamalanathan et al., 2013) to 15-20% in 2019 (Krug et al., 2019). However, this is still quite a low diagnosis rate considering the high prevalence of PCOS across the world.

Physical fitness is quite deeply connected to mental health. Mental illnesses affect 1 in 7 people globally (Ritchie & Roser, 2018). These include many issues, of course, such as depression, eating disorders, OCD, BPD and even different kinds of addictions. What is thus natural is that PCOS and mental health directly affect each other. WHO reports that unipolar depression is twice as common in people with ovaries. For a person already with a mental illness, PCOS could essentially be an added burden. PCOS itself can lead to mental health issues as well. For example, a symptom of PCOS is thickened hair, which is often a cause of body image issues, especially in women, resulting in increased chances of anxiety and depression (Deeks et al., 2011).

Studies clearly show increased likelihood of psychiatric disorders and heightened emotional distress in people with PCOS (Glintborg et al., 2015; Hart & Doherty, 2015; Veltman-Verhulst et al., 2012). Furthermore, the most common disorders - depression and anxiety - are found 2-4, and sometimes 8, times more often in people with PCOS (Karjula et al., 2017). In India, a study of 70 females with PCOS showed that the prevalence of anxiety was 38.6%, while the prevalence of depression was 25.7% (Chaudhari et al., 2018). Yet another cross-sectional analysis by the Australian Longitudinal Study of Women's Health showed that the prevalence of anxiety was 50% in people with PCOS compared to 39.2% in people without it; depression showed a prevalence of 27.3% in PCOS patients and 18.8% in people without PCOS; lastly, the perceived stress was also greater in people diagnosed with PCOS (Damone et al., 2018). Besides those two disorders, people with PCOS also suffer from various other mental health issues, like eating disorders, with binge-eating disorder or BED being quite the enhanced risk (Lee et al., 2018, Krug et al., 2019) and body dissatisfaction as well as low self-esteem

(Himelein & Thatcher, 2006). They also had increased incidents of self-harm (Månsson et al., 2008). A systematic review of various research papers concluded that people with PCOS have higher risks of suffering from depression, anxiety, OCD and BPD, with symptoms being worse in cases of the first three (Brutocao et al., 2018). A case control study furthermore showed that suicide attempts were seven times more common in the group of people with PCOS, than in the group without it (Månsson et al., 2008). In a survey conducted by the Warwick Medical School with 323 people with PCOS, 83.1% of people felt that they did not receive enough information about the long-term implications; moreover, what they did know heavily focuses on fertility issues rather than any other health issue, such as cardiovascular disease risk (Hillman et al., 2020). To add on to that, nearly 75% experienced mental health issues, but only about 35% remember actually discussing them. Therefore, it is established that PCOS and mental health issues overlap greatly.

Several factors affect this correlation, of which three are taken into account in this research paper. The first is age, as it affects awareness of PCOS as well as results in physical and hormonal changes in the human body. The next factor is environment, which is taken in terms of social factors. Lastly, the coping method, or method of managing or dealing with PCOS is looked at. Henceforth, this project will focus on the correlations between PCOS and mental health with three factors concerning them.

1.1 Age

The idea being explored here is the extent to which growing older can aid a person in managing their mental health as well as PCOS. Stressors at a younger age, such as till 25 years old, are usually oriented towards education and career choices. The present generation of teenagers and young adults are already displaying increased rates of mental health issues (Brueck, 2019). At this stage in life, having PCOS largely comprises irregular menstrual cycles, excessive hair growth and acne, which can add to body image issues. Stressors can change later as one grows, because even the phenotypic characters of PCOS change. Oftentimes, with age, PCOS grows from a reproductive disease to more of a metabolic disorder and symptoms include impaired glucose tolerance and increased cardiovascular risks

(Louwers & Laven, 2020). Moreover, a person with PCOS may be diagnosed as infertile, resulting in further worsening of mental health (Kiani et al., 2021).

A major issue is the stigma around diagnosis, and its impact on a person's mental health. Adults tend to hold up a high level of stigma and hence are less likely to seek help or therapy (Conner et al., 2010). Being diagnosed may stop people from seeking help to avoid being labelled or feeling 'different' (Corrigan, 2007), despite even short-term therapy being quite helpful, especially if affinity between the therapist and patient is high (Puri & Treasaden).

Moreover, regardless of location, people with PCOS express dissatisfaction with the information provided to them about PCOS and the needed changes in lifestyle, which points to a greater need of education (Cree-Green et al., 2017). As PCOS affects 10-15% of the worldwide population of people with uteruses, it is a rather grave concern that people with PCOS not only do not know enough about PCOS before their diagnosis, but after it too.

1.2 Environment

The word 'environment' here refers to, not the physical surroundings of the person, but the immediate socio-cultural surroundings as an indirect measure of their comfort to talk about it. Stigma around polycystic ovarian syndrome and mental health has resulted in the two issues becoming taboo in many parts of the world. While the conversation around mental health has slowly increased in recent times, PCOS remains an issue that many are not well-aware of.

It is necessary to note that age is closely linked to socio-economic and cultural factors. PCOS is often diagnosed during the reproductive ages of a person with ovaries. This is also around the same age that people get married, particularly in the Indian subcontinent where menstruation itself is often taken as a sign of maturity, regardless of the person's actual age or mental maturity. The minimum age of marriage in India for females is only 18 - this means that people tend to get married around this age, regardless of completion of education. An analysis of 2972 marriages from 1982-88 revealed that in 'urban' India, females married before the age of 18 was 28.9%, quite close to the 36.8% in rural India (Sivaramet et al., 2008). As of 2014, the average age of women marrying in the rural areas was 21.8 years and

in urban areas, it was 23.2 years (Ngilneii, 2018). Regardless of that increase, it is very likely that it is not just age, but the social factors that come with age that exacerbate the situation of a person with PCOS. However, it must also be emphasised that this fact applies to people more in India, and in the Indian subcontinent, and not the world. In Western countries, it is unlikely for a person to marry at a young age - the average age of marriage for women is 28.1 years in the United States in 2020 (USC Bureau, 2020), and 31.5 years in the United Kingdom in 2016 (Ghosh, 2019). Such factors must thus be kept in view when taking socio-cultural environments into account.

In India, as well as in other countries of the Indian subcontinent, menstruation itself is not openly talked about. Hence, the most easily observable sign of PCOS - that is, irregular menstrual cycles - is often pushed aside for a long time. A study conducted in an urban slum showed that only six out of 52 women knew about menstruation - they only knew about it due to their friends reaching menarche earlier (Garg et al., 2001). The same study also noted the negative emotions, such as shame, fear and shock, that surrounded menstruation - with period blood being termed ‘dirty blood’. In another study on the socio-cultural impact of PCOS, it was found that menstruators are urged against talking about menstruation with even their fathers (Sharma & Mishra 2017).

PCOS is also often a cause of infertility. The culture in South Asia also considers women unable to give children as ‘inferior’, thus creating a stigma. In Pakistan, a case study on the socio-psychological effects of infertility showed that infertility was the main case of several mental health issues including, but not limited to, anxiety and depression, along with domestic violence (Siddiqui & Tabassum, 2017). In a similar manner, Indian infertile women with PCOS are seen as ‘defected’, and even looked upon as mere servants to finish household chores as they could not bear children (Sharma & Mishra, 2017). The same study furthermore found that most women do not seek treatment until infertility crops up as a problem to be faced with a doctor. Two respondents were even told that the cause of their infertility was nothing but ‘black magic’ - and hence, they could not visit doctors for help. Clearly, such misconceptions can also become not only part of the reason why people with PCOS are under-diagnosed, but also why they are unable to seek help for it or talk about it comfortably with the people who are close to them.

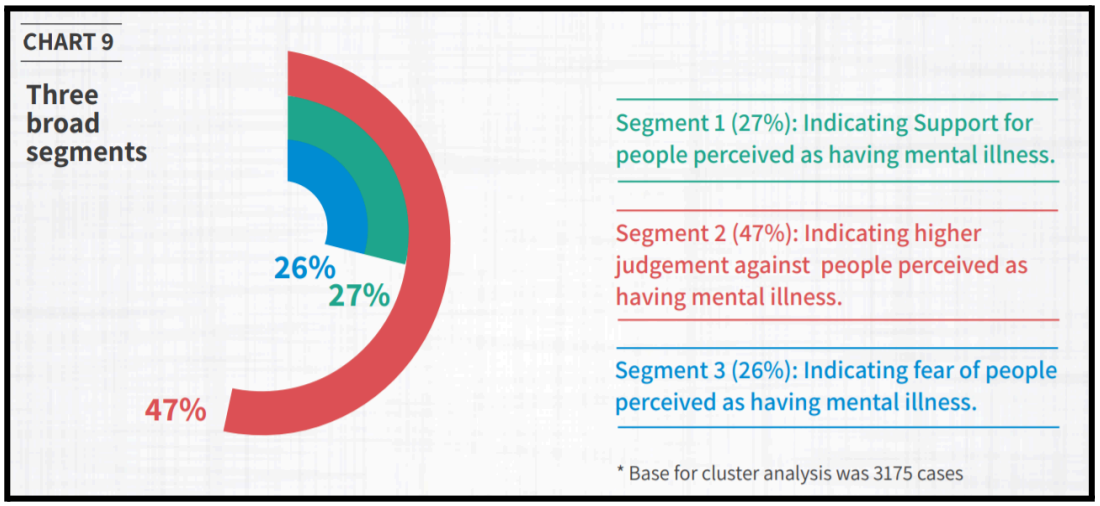
Unfortunately, this is not merely a cultural problem limited to the Indian subcontinent, or even South Asia: research conducted on the social consequences of infertility in Iran revealed that infertile people with uteruses faced social exclusion and domestic violence, and went as far as imposing isolation upon themselves due to the heavy stigma around them (Hasanpoor-Azghdy et al., 2015). Families, including significant others, as well as whole communities discriminate against such people too, according to the same study.

Such taboos and discrimination only naturally stop menstruators from seeking discussing menstrual health and hygiene, thereby preventing them from seeking treatment for conditions like PCOS.

A barrier similarly exists around the conversations of mental health. Again, the barrier is stronger in South Asia. A survey undertaken by The Live Love Laugh Foundation in the year 2018 in India revealed that 62% of participants used derogatory words for people with mental health issues, and 71% displayed stigma around the topic. Adding on to that, 60% of the participants even believed that people with mental health illnesses should remain far from others to avoid contaminating them. Furthermore, 47% of people seem to hold high judgement against those with mental illnesses.

Figure 1.3

Perception of people in India towards people with mental illness (The Live Love Laugh Foundation, 2018)



Naturally, if this is the state of mental health in India on the whole, the condition seems worse for people with assigned female at birth or those who are women. In rural India, a study found that common mental disorders in women were directly related to socio-economic factors like low income, low education and low standard of living as well as issues that are gender-discriminatory and patriarchal, such as husbands using alcohol and husbands being dissatisfied with the dowry (Shidhaye & Patel, 2010).

To sum up a few points, a variety of factors play into the construction of the barrier of mental health. In places like India, the barrier is built out of sex, gender and socio-economy that add to the pre-existing stigma of mental health illnesses. Physical issues are difficult to discuss in a socio-cultural environment where even menstruation cannot be discussed, much less problems regarding menstruation. People with PCOS and mental health issues thus face stigma for both their physical and mental health issues, resulting in a greater discomfort to talk about either. This only worsens their mental health. From March 2015 to May 2016, a study was conducted on 100 patients (assigned female at birth) admitted to the ICU after attempting suicide - it led to the finding that 14% had PCOS (Gupta et al., 2017). Moreover, the same study showed that depression was displayed in 57% of these cases.
Therefore, it can be concluded that socio-cultural surroundings have a major role in the conversations around the mental health of people with PCOS.

1.3 Coping method

Regardless of whether an illness is physical or mental, coping methods become necessary, especially if the illness is long-term. Many coping methods overlap for physical and mental issues. For example, exercise can help release stress and thus improve mental health; it can also help reduce weight, which is helpful for PCOS where weight gain tends to be an issue - hence, it helps their physical health, and also helps their mental health as weight gain is often accompanied by body image issues. Although ways to manage PCOS and mental health and coping with issues that crop up can vary from one person to another, the most common ones include exercise, medication and certain types of diets.

Lifestyle modifications are typically the most helpful and thus form the base of treatment for PCOS patients in order to reduce the chances of long-term health problems like cardiovascular disease, cancer and diabetes (Bates & Legro, 2012). One such change could be a change in diet. While this is typically for the patients who are also overweight, people may also find that certain diets aid in reducing acne or even help regulate the menstrual cycle. It is worth pointing out that, again, there is no diet that universally helps people with PCOS deal in dealing with the syndrome. More often than not, it merely acts as an aid. In some cases, PCOS patients find intuitive eating to be better than following a diet.

Many PCOS patients follow a ketogenic diet, though it is, as aforementioned, not a universally helpful diet. A ketogenic diet, or keto diet in short, is defined as a high-fat and low-carbohydrate diet. Through this, the body enters the state of ketosis; instead of using carbohydrates for energy, it begins burning up the fat, thereby resulting in loss of weight. As it does not work for everyone, it is naturally highly recommended that a person with PCOS work with a nutritionist if they choose to follow the diet. Although the long-term effects remain somewhat uncertain, studies do suggest that a ketogenic diet can help with weight loss and insulin resistance (Yancy et al., 2004; Boden et al., 2005) and PCOS in general (Mavropoulos et al., 2005). A case study found that a modified ketogenic diet, where the main source of calories is protein instead of fat (protein-sparing modified fast diet) can in fact aid in restoring fertility; out of the four women with PCOS in the case study, two were able to conceive without the need to induce ovulation (Alwahab et al., 2018).

A noteworthy point is that diets and mental health seem to have inconsistent trends, as per a systematic review of 12 epidemiological studies (O'Neil et al., 2014). Diets that focus on weight loss, though, do have a positive psychological impact (McClernon et al., 2007), though it is worth questioning whether this impact would have any effect if not for the eurocentric standards of beauty focusing on slimmer body shapes in the past couple of decades.

Exercise, as aforementioned, helps with PCOS and mental health for very clear-cut reasons. PCOS and insulin resistance are rather closely linked. A study of 271 people with PCOS revealed that almost 65% of them were insulin-resistant (DeUgarte et al., 2005). Insulin

resistance leads to gaining weight, and therefore is often a cause of body image issues. In comparison to a diet, exercise may be more helpful, which was proved by a study performed on two groups of PCOS patients: although both showed improved menstrual cyclicity, the ones that took the exercise program also showed a higher ovulation rate (Bates & Legro, 2012). Hence, physical activity helps with maintaining weight, and is thereby strongly linked to better mental health.

In a survey of 153 people with PCOS, those who performed physical activity showed less severe depression in comparison to those who were physically inactive (Banting et al., 2014). Another study found that aerobic exercise improved sexual function as well as anxiety and depression in people with PCOS (Kogure et al., 2021). It is thereby established that exercise typically has a positive correlation with management of PCOS and mental health.

Medication naturally covers various kinds of medicine. This could be birth control pills, which are essentially oestrogen and progestin - these can help in regulating menstrual cycles for people with PCOS (LeDuc, 2019). One such medicine, spironolactone, aids in blocking the effects of androgen. Furthermore, people with PCOS are likely to have more severe depression and anxiety (Karjula et al., 2017), so it is also highly probable that a person with PCOS also takes medication to manage their mental health. Unfortunately, research on the aspect of medication taken by PCOS patients for their mental health issues is extremely inadequate. Research into drugs that are directly related to managing PCOS is much greater.

Metformin, for example, is typically prescribed for treatment of diabetes, but due to similar insulin-resistance in PCOS patients, it is prescribed to them as well, albeit usually in lower doses. In a case study of 18 obese PCOS patients, taking metformin resulted in improved menstrual cyclicity; moreover, the level of androgens (testosterone, androstenedione and free testosterone) reduced significantly (De Leo et al., 2006). Another study suggested that while metformin can help people with PCOS, it depends on their insulin resistance which is not even a universal sign of PCOS; furthermore, long-term studies are not yet enough to prove that the benefit is good enough to begin medication that can last decades (Duleba, 2011).

Drugs may also be used in combination to help with PCOS on the whole. However, several factors are taken into consideration when prescribing medication, some of which may be:

- Age
- Phenotype/symptoms
- Medication previously prescribed for other physical or mental illnesses or presenting symptoms, such as irregular cycles or acne

Therefore, medication is a rather complex issue. It is necessary for people with PCOS to exercise caution when taking different medicines. Moreover, it is best to consider healthcare at the earliest - the sooner PCOS is diagnosed, the more likely it is for the patient to take care of themselves appropriately and avoid worsening conditions. Lastly, it's best that while medication is taken, other coping techniques are also used to manage PCOS in the long term.

Finally, what is most important to note is that there exists no singular way to optimally manage polycystic ovarian syndrome and mental health. While some may find medication to be the best manner of management, others may look towards more holistic approaches, such as lifestyle changes. The choices depend entirely upon the person.

OBJECTIVES

OBJECTIVES

The aim of the dissertation is to shine a light on the factors that affect the relationship between polycystic ovarian syndrome and the mental health of those who have it.

Through the analysis of the compiled data from the survey, the following questions should be answered:

- How does a person's age affect their experience of PCOS, and their ability to converse about their mental health?
- To what extent does socio-cultural environment affect the mental health of a person with PCOS and their conversations about it?
- How do people with PCOS manage their physical and mental health?
- Is the mental health of people with polycystic ovarian syndrome being prioritised enough?

CHAPTER 2
REVIEW OF LITERATURE

CHAPTER 2
REVIEW OF LITERATURE

Medical research is a field that can continue infinitely: diseases and syndromes are yet to be discovered, yet to be studied from different aspects (whether it be biochemical, physical, or genetic), and yet to be treated and cured. One cannot deny though, that despite medicine being entirely based on science, it is not free from bias.

A major bias is sex and/or gender. People assigned male at birth are often the preferred participants due to the reduction in fluctuating hormones during menstrual cycles, and research on people assigned female at birth is limited for the same reason. Researching the latter becomes rather difficult as the response of participants may vary upon the stage of their menstrual cycle; moreover, even in cases where people assigned female at birth were included in the research, the sex differences remained unaccounted for (Holdcroft, 2007). Furthermore, since research has always been performed on people assigned male at birth, others were excluded from further research due to lack of physiological data (Söderström, 2001). Another reason was the use of hormonal contraceptives by people assigned female at birth, though this has lately been taken into account (Holdcroft, 2007).

An unfortunate result stemming from this bias is that conditions like polycystic ovarian syndrome are heavily under-researched. Another reason that PCOS is not studied effectively enough is due to the fact that it can develop any time after menarche, and its symptoms can decrease or continue even after menopause (Brown, 2015).

Moreover, even the research that does exist on PCOS focuses largely on the analysis of quantitative data; qualitative data about the experience of having PCOS is yet to be collected. In fact, one of the first studies to take into account the quality of life of people with PCOS and accompanying co-morbidities (including living with depression or suicidal tendencies) was conducted only in 2015, which is quite recent in terms of medical research (Williams et al., 2015). This means that the psychological effects of PCOS, from basic issues like stress to

more severe mental health illnesses like bipolar disorder (BPD) or obsessive compulsive disorder (OCD), are not studied enough, resulting in people with PCOS also having rather limited knowledge about it (Hadjiconstantinou et al., 2017). As mentioned in prior content, polycystic ovarian syndrome also presents itself with varying symptoms, causing people to have different experiences more often than not. Consequently, methods and medications to help people with PCOS and mental health are various, with none being universally helpful.

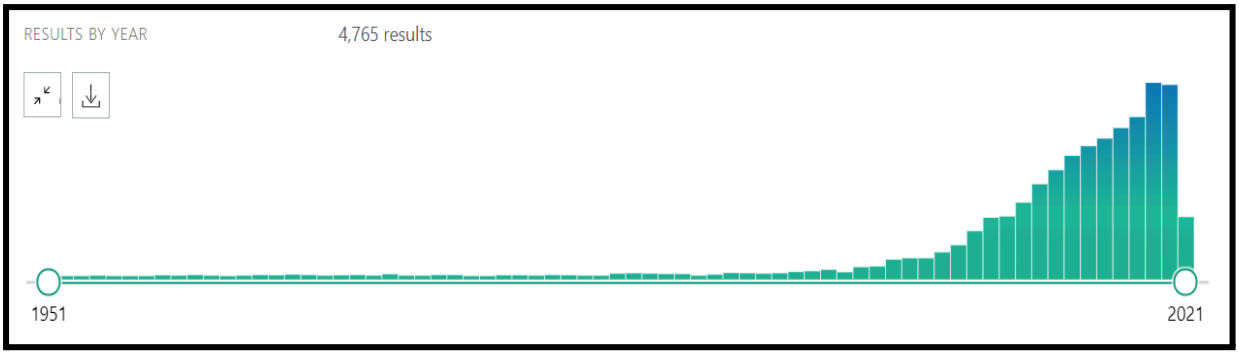
Needless to say, this means that research into the relations between PCOS and mental health is not quite as intensive or extensive as it should be, especially in the long term, thereby resulting in lessened literature than one would prefer. However, the research papers that do look at this intersection generally provide an excellent view.

Research on PCOS has increased in the past couple of decades, and particularly more so in the last five years. This could partly because the awareness around it has increased. Adding on to that, the criteria has differed over the years. The 1990 NIH criteria stated that the diagnosis of PCOS required the person to have hyperandrogenism and anovulation, and required all other diagnoses to be cancelled out first. The Rotterdam criteria of 2003 said that 2 of 3 criteria must be fulfilled: hyperandrogenism, anovulation and/or polycystic ovaries. The 2006 AEPCOS definition remained almost the same, but said that hyperandrogenism was a necessity, along with at least one of the two remaining options. Nowadays, the most commonly used criteria is that of Rotterdam; this has resulted in increased cases of diagnosis as it does not necessarily require the exclusion of other issues, even though it is certainly taken into account (as it should be to avoid wrong diagnoses). The definite criteria also allowed for further research as the number of people with PCOS grew, resulting in it becoming a larger concern, and at the same time, easier to study due to a larger number of participants for research.

On PubMed, a search of ‘polycystic ovary syndrome’ presents the chart in Figure 2.1 for the number of studies through the years, where it is visible that research picked up a little more during the years 2018 and 2019:

Figure 2.1

Search for 'polycystic ovary syndrome'



However, there's quite a stark difference for the results of 'polycystic ovary syndrome mental health' and 'PCOS mental health' respectively, as shown in Figures 2.2 and 2.3:

Figure 2.2

Search for 'polycystic ovary syndrome mental health'

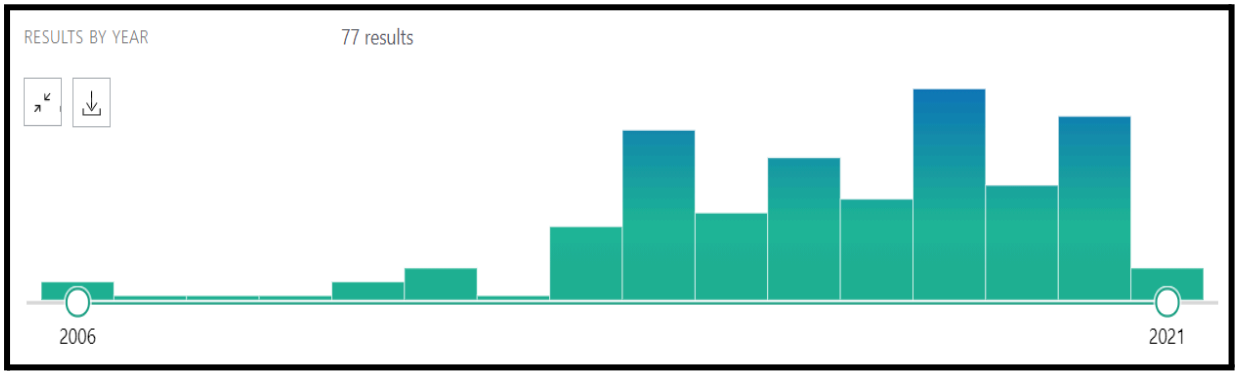
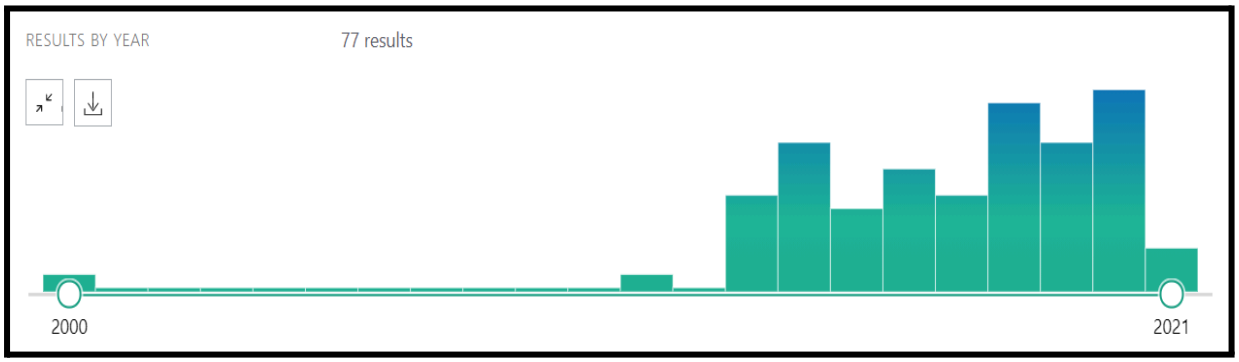


Figure 2.3

Search for 'PCOS mental health'



Even if it is assumed that the two searches have different results, they still add up to only 154 papers, which is 3,2% of the research on PCOS and papers related to it. As aforementioned though, the existing research, despite its limits and limitations, is still important.

2.1 Literature review of basic research into PCOS

Some of the earliest well-written papers discussing the intersection between polycystic ovarian syndrome and the impact of it on mental health are from the early 2000s. One such review paper, by Melissa J. Himelein and Samuel S. Thatcher (2006), forms a strong foundation of the relations between PCOS and various mental health issues, from stress and depression to BPD and eating disorders. The review covered about 15 years of research and solidified the connection that PCOS can be a major factor in either resulting in a mental illness or worsening a pre-existing condition. It furthermore spoke of management which covered treatment of various symptoms, from laser treatment for acne to diets regarding weight issues.

Mansson's study from 2008 with a control group of people without PCOS and a group of people with PCOS strengthens the foundation set earlier that mental health issues, especially depression, anxiety and suicidal ideation, are a greater concern for people with PCOS. It highlighted the lessened quality of life for people with polycystic ovarian syndrome. However, it does not address other mental illnesses, which acts as a limitation, especially because depression can often accompany mental illnesses like BPD. This is, of course, understandable as it was still one of the more initial studies.

Moving on towards the next decade, work on PCOS saw a slight spike. The review article on the consensus of health surrounding people with PCOS by Fauser et al. (2011) provided a clear view of the knowledge available and the gaps that needed to be covered about PCOS at the time. As this paper is being written 10 years later, it shows how far research has come, and how many more gaps have been recognised. Furthermore, the paper was written with each topic covered systematically with the statistics available at the time, thereby also setting a standard for papers written now. In a similar way, the review paper by Veltman-Velhurst et

al. (2012) covered 28 studies and solidified the connections between PCOS and various mental illnesses like depression and anxiety, highlighting their high prevalence.

Other papers, such as those by Glintborg et al. and Hart & Doherty in 2015, were focused on Denmark and Australia respectively. This proved that mental health was strongly connected to PCOS, regardless of the person's location in the world. Although the former was also an excellent paper on the prevalence of type 2 diabetes, it was unfortunately not quite helpful for studying mental health. Work by Hart & Doherty (2015), on the other hand, proved that the mental health of people with PCOS was a much larger concern than physical health as more patients were hospitalised for the former, hence the need for more research and focus on such a topic.

Studies from 2016 and onwards proved to be the most helpful. Gibson-Helm et al.'s study from 2016 was particularly important in understanding how tough it is to be diagnosed with PCOS, and even then, have little information to go on with actually managing it. The review by Brutocao et al. (2018) also reinforced the same point: the mental health of people with PCOS needed more attention as they were more likely to have mental illnesses. The gaps, despite the ongoing research, are still very wide.

Karjula et al. performed a study in 2017 where they had a follow-up with their participants after 15 years, and again, their depression and anxiety had not improved over time at all, thus reinforcing the point that there needs to be better support. Another study by Damone et al. in 2018 confirmed the same. Lee et al. (2018) wrote a review which confirmed prevalence of eating disorders, which is a significant point to be added as previous research had primarily focused on depression and anxiety. The same was also provided by Krug et al. (2019), along with the latest statistics of the worldwide PCOS incidence. Hillman et al.'s paper from 2020 was based in the UK, and confirmed that long-term research of PCOS and its effects needed more attention.

With regards to research in India, an extremely important study was the one by Chaudhari et al. (2018) as it researched the mental health of PCOS patients specifically within the country, and put into the spotlight the lack of Indian research and literature on PCOS. Rathour &

Singh (2020) also emphasised on the method of diagnosis of PCOS, which helped in understanding the need for universal criteria to be set, as well as the need for better understanding by doctors themselves. The fact that only two papers from India were genuinely helpful for this study also points at the need for further research.

2.2 Factor-wise literature review

The paper focuses on three factors: age, environment and coping methods. Each study typically focused only on one of these factors, which is why the literature will be discussed separately for each factor.

Studies by Corrigan (2007) and Conner et al. (2010) focused on how increasing age shows a correlation with increased stigma about the diagnosis, and thereby the treatment, of mental illnesses. This was important in understanding how a mental illness diagnosis after a PCOS diagnosis can make treatment tougher for both as the openness of the conversation decreases. Louwers & Laven (2020) covered the various characteristics of PCOS through life, which shows that mental illnesses can also differ accordingly (for example, if weight gain is not a problem, then body dissatisfaction or eating disorders are less likely). The commentary by Cree-Green et al. (2017) on work by Gibson-Helm et al. (2016) focused on the need for education about PCOS. Another systematic review by Kiani et al. (2021) showed the prevalence of depression in people with infertility, which is a significant characteristic of PCOS as well. However, it did not focus on PCOS, and hence was not a good measure of how far infertility caused depression in people with PCOS.

The immediate socio-cultural environment of people with PCOS has been researched relatively more in India. This is largely due to PCOS sometimes resulting in infertility - a piece of news that can weigh down the person due to societal stigma, especially at a younger age. Garg et al. (2001) studied the socio-cultural aspects of menstruation , which was a good indicator of how little PCOS is talked about. The statistics from a study by Sivaramet al. (2008) showed that marriages have happened at an earlier age in India than other parts of the world, thereby suggesting menstruation was likely talked about even less. Shidhaye & Patel (2010) proved that socio-economical and cultural factors played a role in mental health too.

Then, two studies by Hasanpoor-Azghdy et al. (2015) in Iran and Siddiqui & Tabassum (2017) in Pakistan revealed the negative socio-cultural consequences of infertility, thereby showing how mental health can be affected by it. However, all of these studies were indirect measures of what people with PCOS may face. The most important studies were thus the ones by Gupta et al. (2017) and Sharma & Mishra (2017) were crucial in understanding how PCOS and mental health affect each other in terms of age, culture, marital status and various other factors as well as the knowledge they had about polycystic ovarian syndrome.

The last factor is coping methods, which as explained previously, can include various techniques. Bates & Legro (2012) studied the long-term management of PCOS, concluding that more research was definitely needed. An important link they recognised was that of the one between PCOS and weight gain. Similarly, work by DeUgarte et al. (2004) concluded that insulin resistance, and thereby weight gain, was not a universal symptom, but still quite common. Hence, it was deduced that diets were often quite important for people with PCOS. Ketogenic diets were of particular interest. Research by Yancy et al. (2004), Boden et al. (2005) and McClernon et al. (2007), though of not great importance to this paper, pointed towards the positive side of ketogenic diets for PCOS by improvement of weight management. Neither, however, looked at the long-term consequences. Case studies by Mavropoulos et al. (2005) and Alwahab et al. (2018), however, were quite significant as they looked at the effects of such diets specifically on people with PCOS, and showed that there was a significant improvement. One limitation in both, though, was a very small number of patients, which may have given inaccurate overall results. Nevertheless, both came to the same conclusion despite being years apart, which implies that it is quite likely that a ketogenic diet can be of aid to a person with PCOS who is focusing on weight loss or management.

Be that as it may, diets are not always good for mental health. O'Neil et al (2014) reviewed 12 studies which showed somewhat inconsistent trends, suggesting that diets may or may not have a positive impact on mental health. This aspect certainly requires more exploration.

Another common option is medication, which also has been looked into, but still has great space for improvement. Duleba (2011) looked into several medicines, thus providing an

excellent perspective into the options available, and to what extent each is helpful. Of these, Metformin is the most common, which is why several other studies have focused on it. De Leo et al (2006) showed that Metformin was helpful for people with PCOS who needed to lose weight. Having said that, Duleba (2011) also rightly pointed out that there is again, not enough research to prove whether Metformin is good for the long-term. Hence, work by Duleba (2011) was definitely extremely significant in learning about this.

Limited research is available on the effect of physical activity on people with PCOS and their mental health. In fact, recent research by Kogure et al. (2020) is quite important. It did have the limitation of highly varying body mass indices, but regardless of that, it showed physical activity generally helps people with PCOS. The most important study was by Banting et al. (2014), as it focused on the association between physical activity and mental health in people with PCOS. Moreover, it also took into account the body mass indices, which was absent in the work by Banting et al. (2014). Adding on to that, it took in specific motivators of exercise as well, which would indicate how PCOS patients themselves feel about exercising, regardless of whether it's a requirement for them.

In essence, there most certainly exist several gaps in the research for polycystic ovarian syndrome. Mental health needs to be looked into, especially for long-term management.

CHAPTER 3

MATERIALS AND METHODS

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This research paper required collection of data which was essentially the experiences of people with PCOS. This comes under descriptive research (Kelley et al., 2003). Hence, an online survey was designed using Google Forms in order to collect the required information. The reason for choosing a survey was to collect information from a large number of people in a short time. Moreover, the survey was taken online as the COVID-19 pandemic resulted in restricted entry to hospitals and clinics; people themselves were cautious about being outside, hence the need to ensure that the survey could still be available to as many people as possible. As it was online, it was also possible to take into account people from various countries, rather than only within India. A few of the responses were, however, taken within India after the restrictions were lifted. Precautions such as wearing masks and social distancing norms were followed to ensure the safety of the participants.

3.1 Subjects

Sample size

In order to calculate a minimum sample size, the first step was to take into account the number of people with PCOS. Polycystic ovarian syndrome affects approximately 10% of people assigned female at birth in the world (Firstpost, 2020). It should also be taken into account that PCOS occurs during the reproductive age, which can be taken as around 2,511,954,917 as that is the number of people assigned female at birth who are now between 15 and 64 years old (Countrymeters, 2021). Therefore, it means that approximately 2,511,954,92 people are affected which would be the population size for the survey.

The number of participants of the survey was 357. Using an online calculator designed by CRS, this meant that at a confidence level of 95% or Z-score of 1.96, the margin of error or confidence interval was 5.19%. Typically, a 5% margin is acceptable. Therefore, this study is likely quite accurate in its results. Although some researchers use a 99% confidence level, the

number of participants required would have been quite difficult to reach. In consequence, the more commonly used confidence level of 95% was used.

Demographics and criteria of subjects

All participants were clearly asked to proceed with the survey only if they have polycystic ovarian syndrome, which acted as the inclusion criteria. This naturally meant that the sampling was non-random. As the criteria was rather specific, and the needed information could not be taken from people without PCOS, this type of non-random sampling was purposive or judgmental (Maxwell, 1996).

All respondents were assigned female at birth. Of the 357 participants, 209 were above the age of 25, 142 were 18-25 years old, and only 5 were below the age of 18. Out of the 357 people, 40 were from India. The remaining were from across the USA, the UK, France, and various other countries. All participants could understand at least simple English as they were able to understand and answer the survey questions, and had likely attained at least high school education. However, their location and education would be of little to no importance to this study. By proceeding with the survey, they volunteered to be subjects in the survey and consented to having their data being used for this research project. Confidentiality and anonymity of identity was assured.

3.2 Survey design and distribution

Survey description

The survey consisted of four sections of questions: General, Age, Environment and Coping methods. Most questions were close-ended, meaning that the participants were given simple statements. They would then give a score of 1-5 depending on how much the statement applied to them, how true it was for them, or how much they agreed with it.. A score of 1 meant that the statement did not apply to them or was not true for their experience with PCOS, or they merely did not agree with it; needless to say, a score of 5 meant the statement was applicable, true in their experience, or that they agreed.

Only three questions were partially close-ended. This meant that the participants could choose from the given options, but they also could choose an ‘Other’ option, and specify their answer if it was not one of the given options. This was necessary as it must be remembered that both PCOS and mental health issues are dealt with and experienced in various ways, and each of those must be respected and studied so as to help others who may have a similar experience. It would furthermore indicate the prevalence of the experience in question.

After the creation of the survey questions, an introduction to the survey was written. It was clearly made known to the participants that their identities would not be revealed in any form, and that the data was purely for research. Also, only people with polycystic ovarian syndrome were asked to continue with the survey. By proceeding, they would be consenting to being a participant of this research project. This concluded the process of designing the survey, after which it was approved by Dr. Jyothi Rani, the project guide.

Procedure of gathering data

The survey was largely carried out online by sharing it across social media platforms. In the month of January 2021, the link was sent across to family and friends through Discord. It was then posted on two platforms: Reddit, in its PCOS community, and on Instagram. The link was sent to Julie Duffy Dillon, a registered dietitian nutritionist, in the month of February, who also posted it on her Instagram story to gather more responses from her PCOS patients. This was done online entirely.

Finally, in March, a few responses were collected by visiting Vilada Hospital in Hyderabad and interviewing some patients. These were collected by printing the survey and asking patients the questions directly for their answers. The survey was thereafter concluded on March 31, 2021.

3.3 Data compilation and presentation

The survey was created on Google Forms, which automatically compiles the answers for each question to give bar graphs for them. The data was opened into a linked worksheet on Google Sheets so as to easily filter and compile data using filter options and formulae. Certain data was also copied to a worksheet on Excel Online for graphs with extensive customisation. Stacked bar graphs were created using Excel Online. Venn diagrams were made using Canva by manually entering each number.

CHAPTER 4

RESULTS AND DISCUSSION

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RESULTS AND DISCUSSION

The survey had 357 respondents. The results have been given in the same order as the sections of the survey, with the analysis of the results for each section given accordingly.

4.1 General

The general section had four statements to know how much PCOS and mental health issues affected the participants of the survey. This was followed by checking which symptoms they had, and then another statement to check if their mental health affected their menstrual cycle.

Results

Table 1.1 shows a clear summary of the results. The majority of the respondents - 37.82% - gave a score of 4 for taking care of their mental health. 14.85% of participants agreed fully with a score of 5. 33.61% of people gave a score of 3, followed by 11.76% giving a score of 2, and lastly only 1.96%, which is just 7 of 357 participants, giving a score of 1. The next statement questioned whether the person with PCOS took steps to manage PCOS. Again, the majority gave a score of 4: 35.29%. This is followed by 28.01% giving a score of 3, 22.97% giving a score of 5, 10.08% giving a 2 and finally 3.64% giving a score of 1.

The next two statements were on the extent to which PCOS affects the daily routine and mental health of the participants. For the effect of PCOS on daily routine, 39.22% gave a 5, 29.41% gave a 4, 15.69% gave a 3, 10.36% gave a 2 and 5.32% gave a 1. Clearly, the percentages decreased rather gradually for the scores from 5 to 1. The effect of PCOS on mental health is clearly quite enormous: 53.95% of participants gave a 5, another 30.51% gave a 4, 10.73% gave a 3, 33.89 gave a 2, and only 1.41% - that is, only 5 of 357 participants - gave a 1. The results are summarised in Table 1.1 . The last statement was about the effect of mental health on the participant's menstrual cycle. As per Figure 4.1, 107 participants were unable to answer this, and of the remaining, the majority (85 people) gave a score of 5.

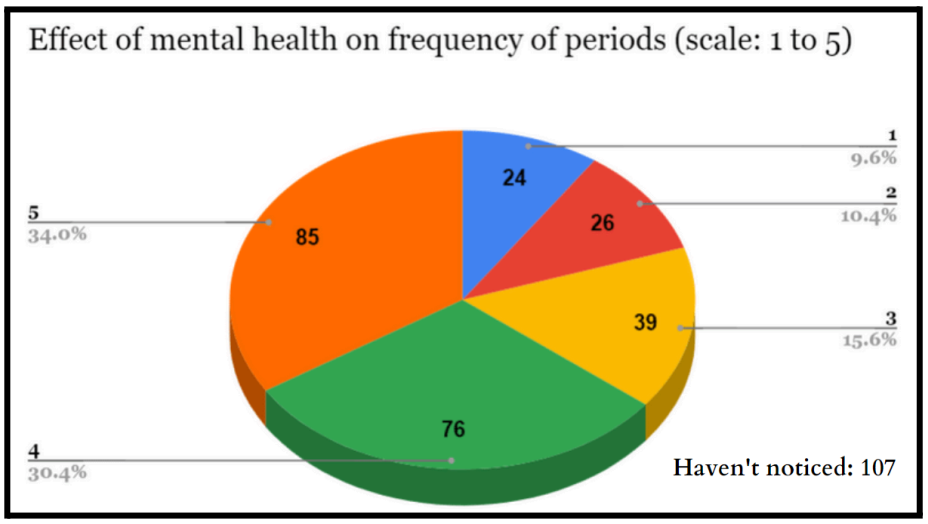
Table 1.1

Respondents scored each general statement on a scale of 1-5, with 1 meaning that the statement was false in their experience, and 5 meaning that it was true

Statement	Number of respondents for each score (percentages in brackets rounded to nearest tenth)				
	1	2	3	4	5
I take care of my mental health.	7 (1.96)	42 (11.76)	120 (33.61)	135 (37.82)	53 (14.85)
I take measures to deal with PCOS.	13 (3.64)	36 (10.08)	100 (28.01)	126 (35.29)	82 (22.97)
PCOS affects my daily routine.	19 (5.32)	37 (10.36)	56 (15.69)	105 (29.41)	140 (39.22)
PCOS affects my mental health.	5 (1.41)	12 (33.89)	39 (10.73)	109 (30.51)	192 (53.95)

Figure 4.1

Pie chart depicting the effect of mental health on frequency of periods in people with PCOS; 1 means very weak effect, and 5 means very strong effect



PCOS and mental health affect each other, thereby resulting in great variation in symptoms. Regardless of such variation, all of them have to be taken into account. Figure 4.2 summarises the participants' responses.

The most common symptom by far was anxiety (88.2% - 314 participants), and then depression (76.4% - 272 people) followed closely by mood swings (72.2% - 258 participants). 81 participants (22.75%) had eating disorders. The eating disorders include anorexia, bulimia, BED, EDNOS and others. However, it must be understood that many of these overlapped. Moreover, there were several types of disorders seen. Only 4 participants seemed to have no mental health issues whatsoever.

In terms of having only a single symptom or mental health issue, depression was seen only in 5 participants, only anxiety in 20, and only mood swings in 7 participants. Besides this, 1 participant had only EDNOS, 1 had only poor self-esteem and 1 faced self-consciousness.

When coupled with other symptoms, the numbers are much greater. The most common combination of mental health issues was anxiety, depression and mood swings: 179 participants (50.28% of total participants) faced these. Out of them, 123 (68.72%) faced only those three issues while 42 (23.46%) also had one or more eating disorders as well. Others had ADHD, BPD, body image issues, etc. Only anxiety and depression were faced by 46 people. 9 of them also had an eating disorder. Next, 32 participants had only anxiety and mood swings. It's also worth noting that 47 respondents had mood swings with an eating disorder, though typically accompanied by other mental health illnesses - only 2 people had only mood swings and an eating disorder.

Figure 4.3 shows the eating disorders faced by people with PCOS. Bulimia is the most common ED, with a total of 27 people with PCOS facing it, of which 8 have it combined with another eating disorder.

Figure 4.2

Venn diagram depicting the mental health issues experienced by the 357 respondents taking part in the survey

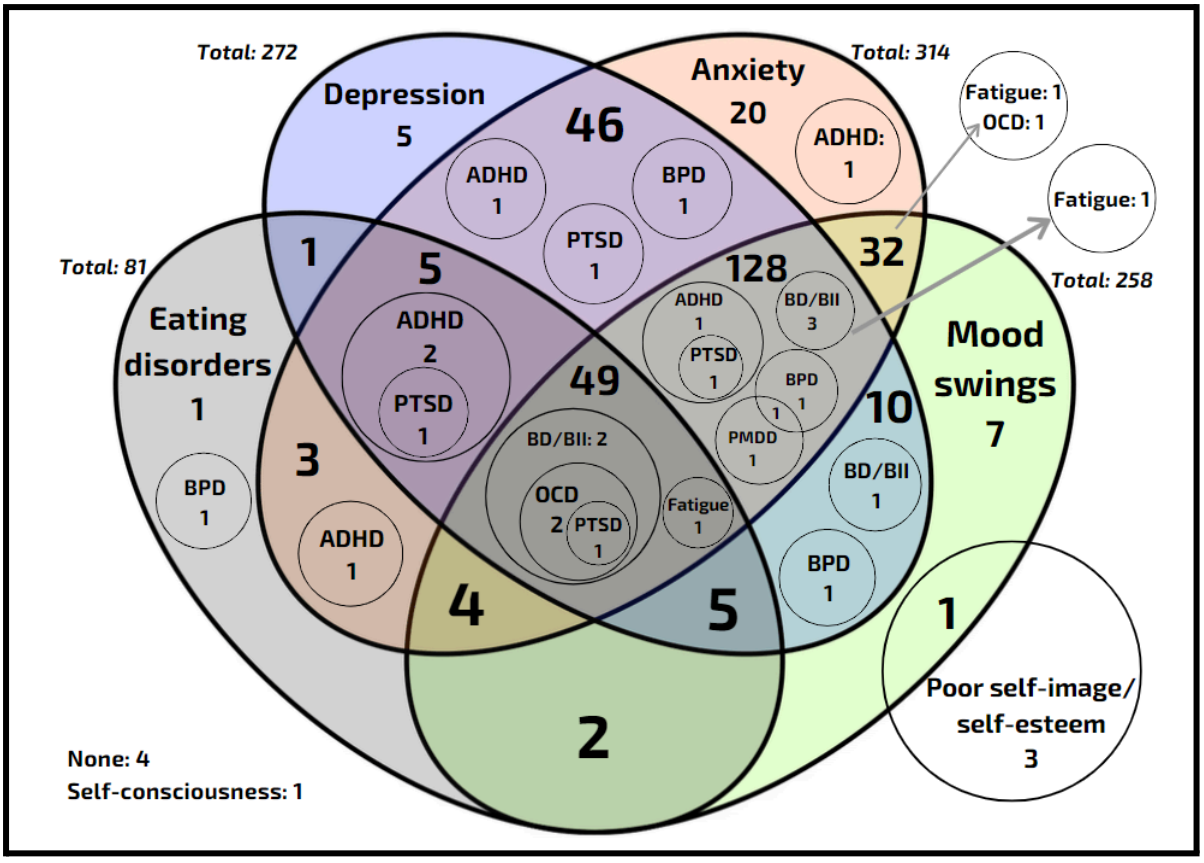
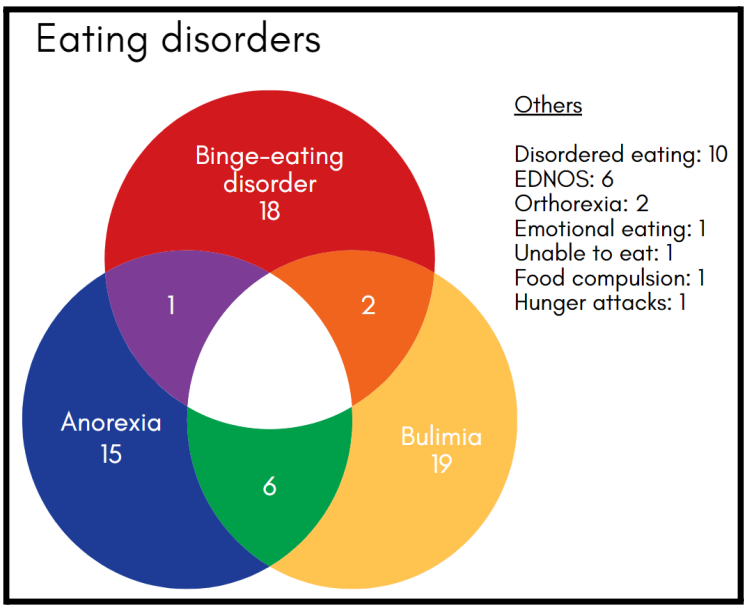


Figure 4.3

Venn diagram depicting the eating disorders faced by people with PCOS



Discussion

The majority of participants gave a score of 4 or 5 for taking care of mental health (total of 52.67%) and PCOS (58.26%). It is worth noting that 29 more people gave a score of 5 for taking steps to manage PCOS, which implies that there is a higher necessity to do so, despite mental health being quite important. Also, 6 more respondents gave a score of 1 for taking measures to deal with PCOS. This could mean that they do not know enough to do so; however, 19 participants said that PCOS does not affect their daily routine. Therefore, it is likely that it is not very necessary for them to take steps specific to dealing with PCOS. However, only 5 respondents said that PCOS does not affect their mental health. Hence, even though it may not affect their daily routine, they should ideally try to manage PCOS in order to ensure better mental health. The last statement in fact clearly shows how closely PCOS and mental health are connected as 53.95% of participants gave a score of 5 for it. Another 30.51% gave a score of 4, thereby forming 84.46% of participants. This total is a lot higher than the scores for taking care of any of the previous three statements. Therefore, it can be concluded that PCOS affects mental health greatly and often affects daily routine, but neither mental health nor PCOS are being taken care of well enough.

The number of people with overlapping mental health issues is enormous. From Figure 4.2, it is quite clear that people with PCOS have depression, anxiety, and mood swings the most often, which aligns with previous research done on PCOS (Karjula et al., 2017; Chaudhari et al., 2018; Damone et al., 2018). There's also a few scattered cases of ADHD, BPD, OCD and PTSD - all of which could easily exacerbate stress and mental health illnesses (Brutocao, 2018).

How common eating disorders are also points to a great crisis. People already try to fit into eurocentric beauty standards; with PCOS, weight gain due to insulin resistance means that losing weight by a diet would not be as easy for people with PCOS than for people without it. This contributes to people with PCOS being at higher risk of eating disorders (Lee et al., 2018). Among EDs, bulimia was found to be the most common. The reason behind this is probably due to binge-eating first, realising that insulin resistance due to PCOS will stop them from losing the gained calories, and then trying to get rid of those calories. Insulin-resistance also explains why binge-eating closely follows bulimia - due to lower blood sugar levels,

people with PCOS are likely to feel hungrier. Anorexia is clearly quite common too, and has the most overlapping with bulimia. The fact that all of these eating disorders exist in over 20% of the survey's respondents confirms that people with PCOS likely are at a higher risk of eating disorders (Lee et al., 2018).

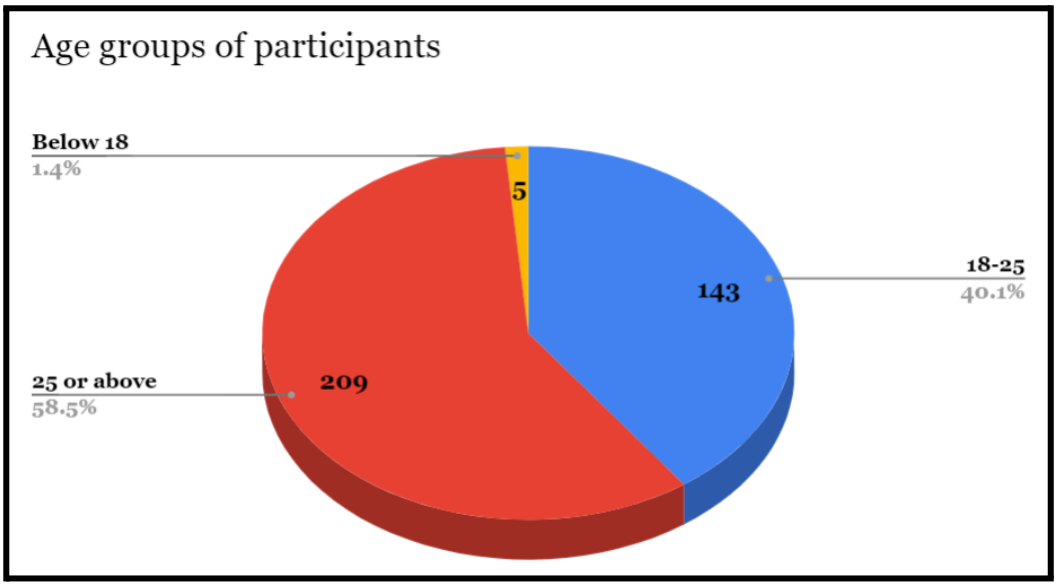
4.2 Age

Results

209 of 357 participants were aged above 25 years old. 143 were 18-25 years old, and 5 were under the age of 18. Figure 4.4 summarises this information.

Figure 4.4

Pie chart depicting the number of participants in each age group



Discussion

The results clearly show that a very minute number of respondents were below the age of 18; the number grows larger as age increases. One reason could be that PCOS can occur at any age, and therefore may have developed later, or worsened with age, resulting in later diagnoses (Louwers & Laven, 2020). However, the ridiculously small number of participants could be because it takes a long time to get diagnosed (Gibson-Helm et al., 2016). Moreover, PCOS is, as seen earlier, attached to several mental health issues, which come with the stigma

around diagnosis (Conner et al., 2010). Even if a younger person is willing to reach out to doctors or health professionals, either they or their guardians may not feel comfortable to do so. Their concern about being labelled or treated differently to their peers can stop them from seeking help (Corrigan, 2007). The small number of participants in this category is a limitation as it means that the results for this age group are skewed. Still, people of this age can, in fact, have PCOS; therefore, more attention needs to be paid, and more information must be available beforehand to them so as to allow them to notice any issues in their menstrual cycles.

The next two age groups of 18-25 and above 25 years old have a larger number of participants. The final age group of above 25 likely also has the largest number of participants as it includes people who are married, or are possibly trying to have children. It's also likely they were diagnosed due to infertility (Kiani et al., 2021).

Age group: below 18

Results

Table 1.2

Number of respondents below the age of 18 with their scores for given statements relating to age and PCOS

Statement	Number of respondents for each score (percentages in brackets rounded to nearest hundredth)				
	1	2	3	4	5
PCOS is easier to deal with as I grow older.	0	3 (60)	2 (40)	0	0
My age has played a role in how comfortable I felt with talking about PCOS.	0	2 (40)	0	1 (20)	2 (40)
My age has played a role in how comfortable I felt with talking about my mental health.	1 (20)	0	2 (40)	1 (20)	1 (20)
I wish I was taught about this when I was younger/in school.	0	1 (20)	1 (20)	1 (20)	2 (40)
Education from a young age can help people with PCOS deal with their mental health in a better way.	0	0	0	2 (40)	3 (60)

Figure 4.5

Graphical presentation of scores given by participants under 18 years of age for given statements about age and PCOS

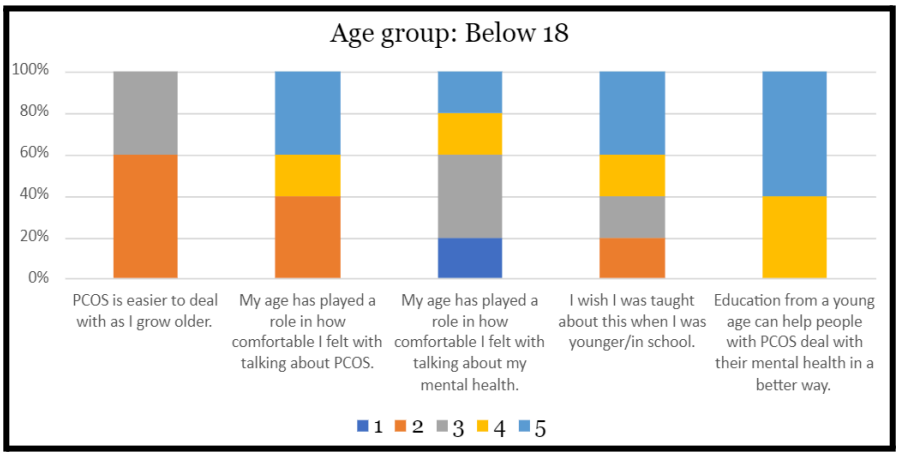


Table 1.3

Individual responses of participants under 18 years of age - their mental health issues, and coping methods for PCOS and mental health

Participant	Mental health issues	Coping method for PCOS	Coping method for mental health issues
1	Depression, Anxiety, Mood swings	Physical activity, reading	Reading
2	Depression, Anxiety, Mood swings	Talking to peers/friends/family	Talking to peers/friends/family
3	Depression, Anxiety, Mood swings, Bulimia	Physical activity, therapy, talking to peers/friends/family, diet/dietary supplements	Exercise/physical activity, Therapy, Diet/dietary supplements
4	Mood swings, Bulimia	Exercise/physical activity, therapy, talking to peers/friends/family, diet/dietary supplements	Exercise/physical activity, Therapy, Talking to peers/friends/family
5	Anxiety, Mood swings	None	Exercise/physical activity, Talking to peers/friends/family

Discussion

The results for this age group, as aforementioned, are likely inaccurate to some extent due to only 5 respondents belonging to it. This could explain why the scores for ease of PCOS management with age are below 4 - they were likely diagnosed quite recently, and therefore do not have much experience to go off on. Age has played a role in their comfort about talking about PCOS more than mental health - this indicates discomfort in discussing PCOS because menstruation itself is not freely discussed in a healthy environment, or there is lack of knowledge around it (Garg et al., 2001, Sharma & Mishra, 2017). Lastly, the five participants leaned towards early education about PCOS in both of the last statements, which displays the importance of knowing about it. The strong feelings likely also come due to the fact that there is not enough information given upon diagnosis (Cree-Green et al., 2017). Hence, the respondents wished they were better-informed as this would have increased their comfort around the topic and helped them in managing PCOS in a better manner - this could have avoided the mental health issues they faced.

As the number of respondents is low, the individual mental health issues and coping mechanisms can be reviewed individually. All five (100%) of them have mood swings, four (80%) have anxiety, three (60%) have depression, and two (40%) have bulimia - one person has all four, which is . If they are more comfortable in talking about mental health but not PCOS, then there remains a gap between how PCOS is connected to mental health. If not for the gap, perhaps it would have been easier for them to cope with both issues. A highly concerning issue is that one of them does not have a way to manage PCOS at all, which again points to lack of resources, information and knowledge surrounding the syndrome.

Age group: 18-25 years

Results

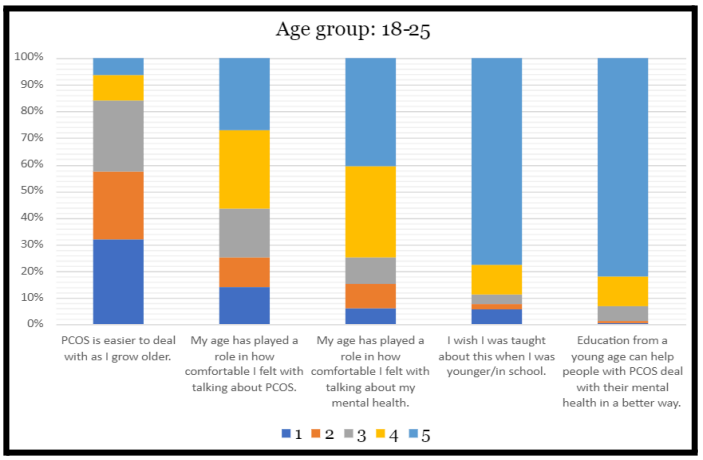
Table 1.4

Number of respondents between 18 and 25 years of age with their scores for given statements relating to age and PCOS

Statement	Number of respondents for each score (percentages in brackets rounded to nearest hundredth)				
	1	2	3	4	5
PCOS is easier to deal with as I grow older.	46 (32.17)	36 (25.17)	38 (26.57)	14 (9.79)	9 (6.29)
My age has played a role in how comfortable I felt with talking about PCOS.	20 (13.99)	16 (11.18)	26 (18.18)	42 (29.37)	39 (27.27)
My age has played a role in how comfortable I felt with talking about my mental health.	9 (6.29)	13 (9.09)	14 (9.79)	49 (34.27)	58 (40.56)
I wish I was taught about this when I was younger/in school.	8 (5.59)	3 (2.10)	5 (3.50)	16 (11.19)	111 (77.62)
Education from a young age can help people with PCOS deal with their mental health in a better way.	1 (0.70)	1 (0.70)	8 (5.59)	16 (11.19)	117 (81.82)

Figure 4.6

Graphical presentation of scores given by 18-25-year-old participants for given statements about age and PCOS



Age group: Above 25 years

Results

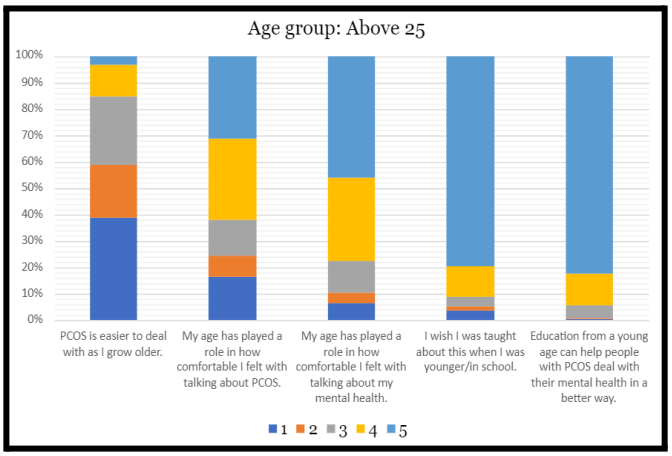
Table 1.5

Number of respondents above the age of 25 with their scores for given statements relating to age and PCOS

Statement	Number of respondents for each score (percentages in brackets rounded to nearest hundredth)				
	1	2	3	4	5
PCOS is easier to deal with as I grow older.	81 (38.76)	42 (20.10)	54 (25.84)	25 (11.96)	7 (3.35)
My age has played a role in how comfortable I felt with talking about PCOS.	35 (16.75)	16 (7.66)	29 (13.88)	64 (30.62)	65 (31.10)
My age has played a role in how comfortable I felt with talking about my mental health.	14 (6.70)	8 (3.83)	25 (11.96)	66 (31.58)	96 (45.93)
I wish I was taught about this when I was younger/in school.	8 (3.83)	3 (1.44)	8 (3.83)	24 (11.48)	166 (79.43)
Education from a young age can help people with PCOS deal with their mental health in a better way.	1 (0.48)	1 (0.48)	10 (4.78)	25 (11.96)	172 (82.30)

Figure 4.7

Graphical presentation of scores given by participants above the age of 25 years for given statements about age and PCOS



Discussion

The overall responses from both groups are extremely similar, which is extremely clear if Figure 4.6 and Figure 4.7 are compared, including the majority giving the same score for each statement. The results can thus be analysed together. In fact, the similarity itself speaks volumes: neither PCOS nor mental health issues truly get better with age. However, growing older has certainly played into increased comfort in talking about both the issues. This somewhat contradicts the study by Conner et al. (2010) that concluded by saying adults have higher stigma; however, this could be due to changing times that allow for more open conversation about both mental health and menstruation, and thereby polycystic ovarian syndrome. Another important point to address is the fact that these two age groups also have nearly 95% of people strongly agreeing that education about PCOS is important from a younger age, and around 90% wish that they were taught about it in school.

Figure 4.8

Bar graph showing extent of agreement with earlier education about PCOS

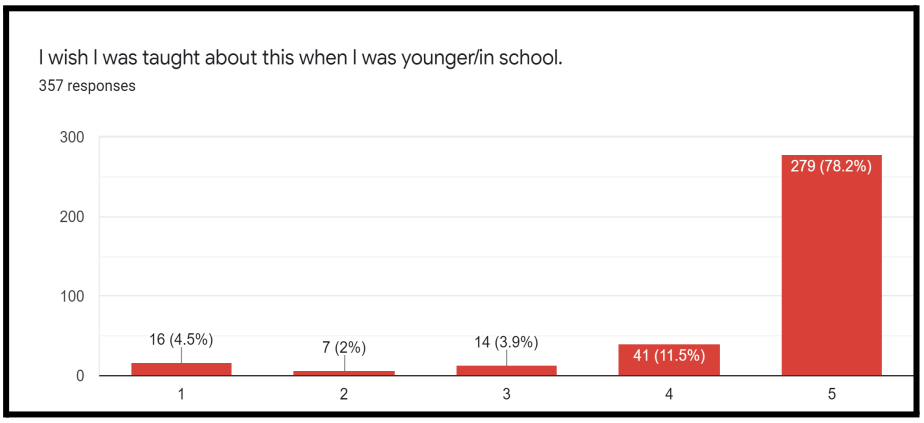
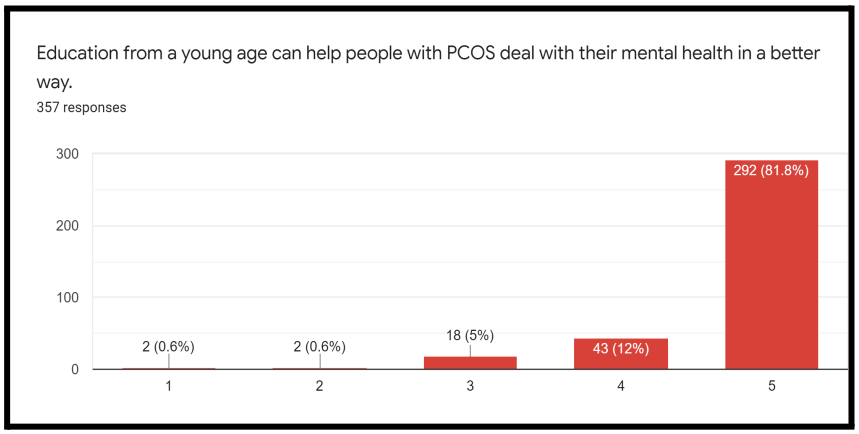


Figure 4.9

Bar graph showing extent of agreement to education about PCOS and mental health from a younger age



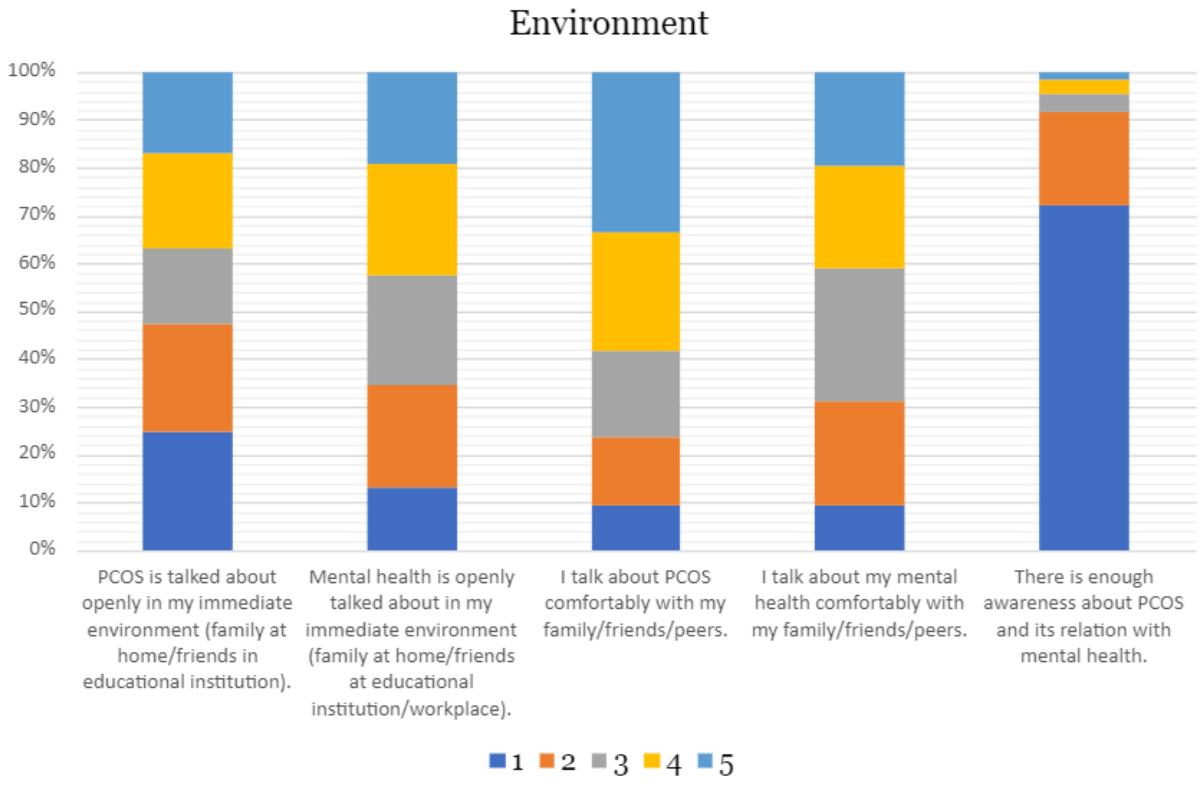
The overwhelming majority of people with PCOS clearly felt the need for earlier education about such an important issue. The need for extensive research and better information at the time of diagnosis could not have been made clearer.

4.3 Environment

Results

Figure 4.10

Bar graph showing extent of agreement to statements about comfort and awareness about PCOS and mental health



Discussion

As expected, Figure 4.10 shows that PCOS is not talked about much - this comes from the fact that most people are in a socio-cultural environment where menstruation is taboo; PCOS being an issue about menstruation would not be spoken about, and results of it (such as infertility) only have further negative consequences (Garg et al., 2001; Sharma & Mishra, 2017; Siddiqui & Tabassum, 2017; Hasanpoor-Azghdy et al., 2015). The score 4 and 5 for PCOS and mental health is almost the same in the first two statements; however, there is

definitely quite a lot of difference for the scores of 1-3, with a heavy learning towards 2 and 3. This means that although it is not as much of a taboo, there is definitely some hesitance, perhaps due to an environment like that of India where mental health illness is extremely stigmatised (*The Live Love Laugh Foundation,* 2018).

However, from the third statement, it is clear that the discomfort arises from the immediate environment of the person, rather than the person themselves feeling uncomfortable. The third statement has over 50% of people scoring a 4 or 5 for talking about PCOS with people they are close to, which means they feel comfortable about it, and yet, it is not spoken about in their immediate environment. Yet, the fourth statement about being open to loved ones about mental health remains similar to the second statement about mental health being talked about. This implies that despite the fact that both, polycystic ovarian syndrome and mental health are serious issues, talking about a physical health condition may be easier or be considered more ‘necessary’ than talking about a mental health condition.

Lastly, it is extremely clear that the dissatisfaction around the knowledge surrounding PCOS and its effect on mental health is too low. Despite the fact that the past few years have brought quite a lot of research on PCOS into light, it simply has not been enough as people with PCOS are still unable to get the information they need and are still finding it difficult in many cases to cope with it.

4.4 Coping methods

Results

Figure 4.11

Venn diagram showing the various coping methods used to manage PCOS

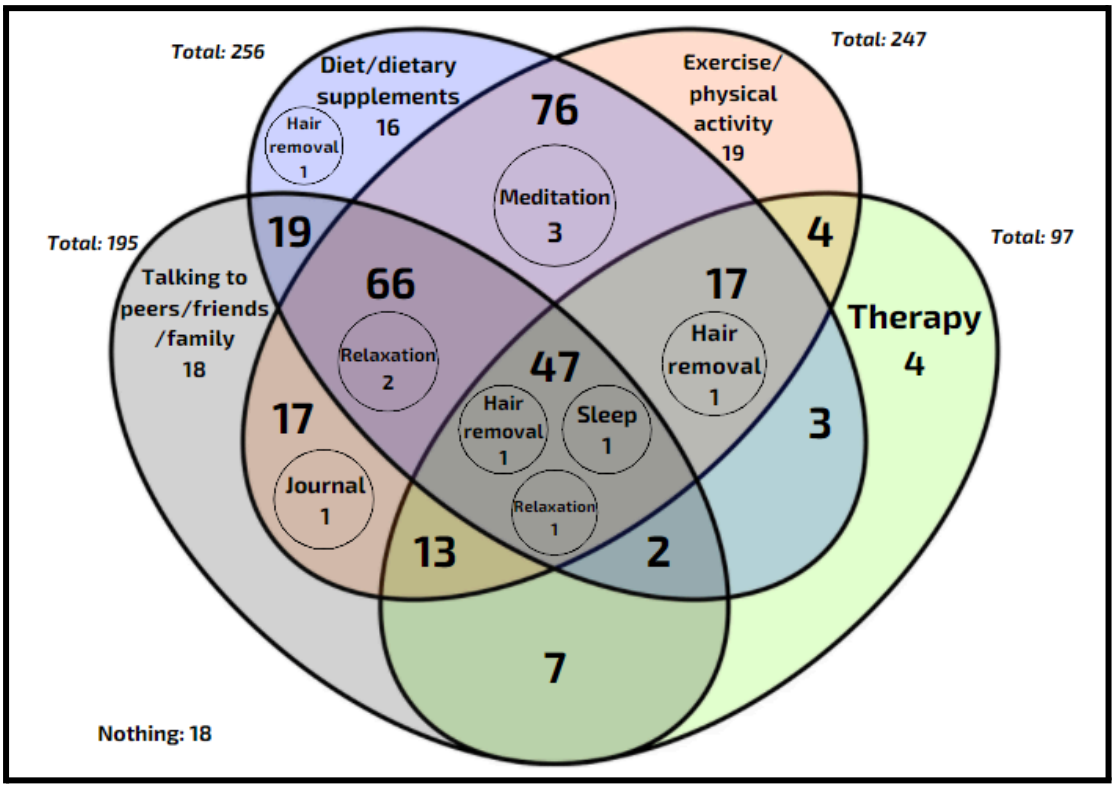


Figure 4.12

Bar graph depicting people's belief in effectiveness of medication for PCOS

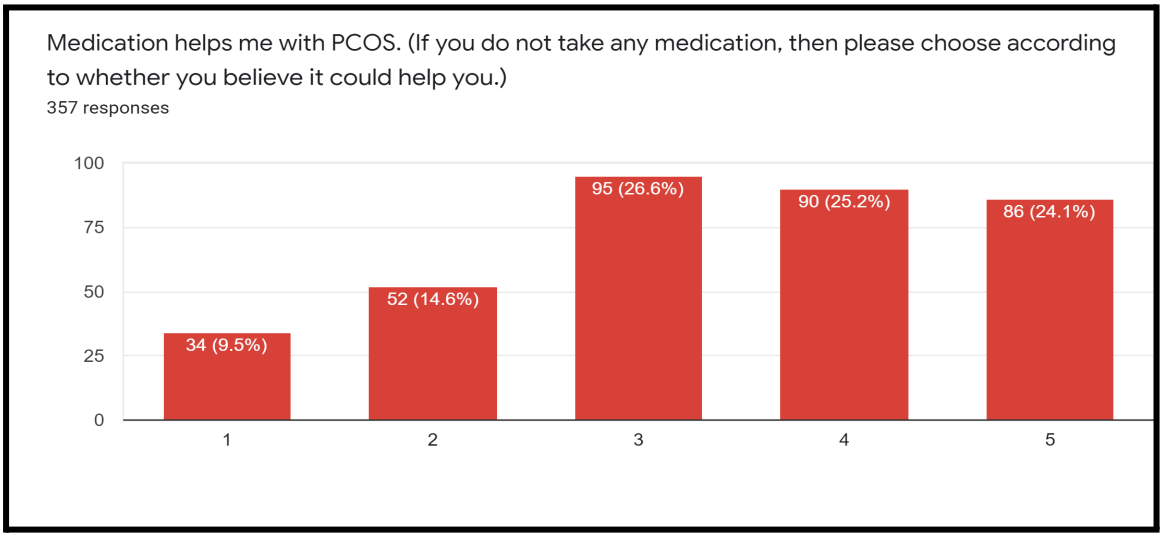


Figure 4.13

Venn diagram showing the various coping methods used by people with PCOS for managing mental health

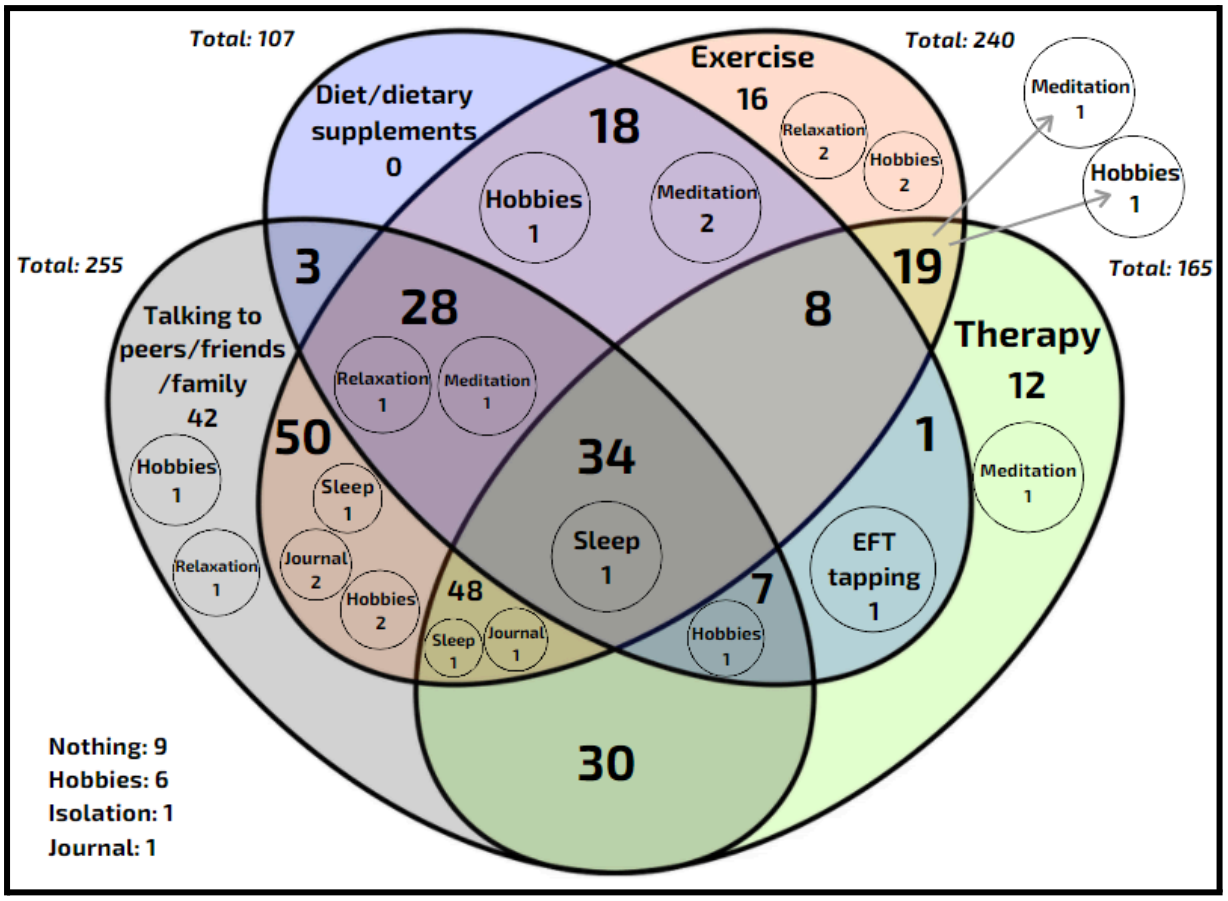
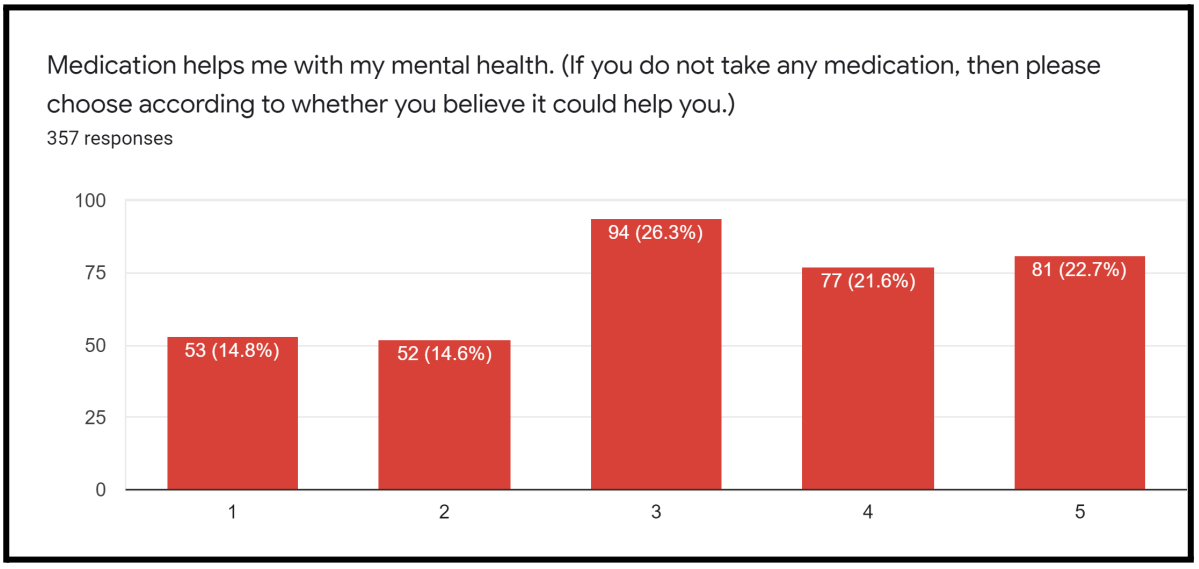


Figure 4.14

Bar graph depicting people's belief in effectiveness of medication for mental health



In terms of a diet, two participants specified intuitive eating, another mentioned a low-carbohydrate diet or a ketogenic diet, while one explained that diets were actually counter-intuitive for them as they may trigger eating disorders.

Also, 7 people mentioned that only medical intervention helped with PCOS. Two of the 7 took birth control, along with 11 others who took it alongside other coping methods. Four also said that they took metformin. Other medicinal options were cannabis, medicinal marijuana and over-the-counter painkillers, essential oils, Chinese medicine and spironolactone.

For managing mental health, 36 mentioned taking medications, of which only 1 has no other coping method. 17 did not mention what type of medicine, while 8 said that the medication was specifically for depression (two medicines specified were Zoloft and Wellbutrin/bupropion).

Discussion

The most common method of dealing with PCOS is with diet and exercise or some form of physical activity - 22.13% of the participants with PCOS chose this coping method. This is closely followed by 19.05% of people choosing dieting, exercising as well as talking to people they feel close to.

The diets are self-explanatory. As previously described, ketogenic or low-carbohydrate diets can help in weight loss which can aid in dealing with PCOS (Yancy et al., 2004; Boden et al., 2005; Mavropoulos et al., 2005).

That said, diets are slightly popular, but not extremely so; moreover, intuitive dieting is essentially not a restrictive diet as other diets are, which suggests that people are recognising that diets do not have consistent positive trends with weight loss, which is to some extent confirmed by the participant who mentioned that diets may trigger EDs (O'Neil et al., 2014; McClernon et al., 2007). Hence, it may not be a genuine positive impact on mental health, or at least not permanent.

Exercise is a coping method that accompanies PCOS, likely partly to help further with weight loss. What is noteworthy is that exercise is followed by 75.35% of the participants while 71.99% follow diets, of which not all are restrictive. This is naturally a step in the right direction because unlike diets, exercise is shown to have helped people with weight loss more than diets (Bates & Legro, 2012), has reduced severe depression (Banting et al., 2014) and anxiety, and improved sexual function (Kogure et al., 2020).

Medication is likely taken in various combinations by the people who did not specify it. Some of the specified ones were birth control and Metformin - both of these can help in regulating menstrual cyclicity (LeDuc, 2019). Similarly, spironolactone, which blocks androgenic effects, is likely helpful for maintaining feminine features.

As depression was found in around every 3 in 4 (76.19%) of people with PCOS, it is only natural that a portion of them are on antidepressants. However, studies regarding the effect of such medicines on people with PCOS is scant. Hence, it is tough to say whether it is a good choice for people with PCOS.

CHAPTER 5
CONCLUSION

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Polycystic ovarian syndrome is not merely a physical health issue as it is strongly connected to mental health. Age, socio-cultural environment and coping methods are three important aspects to it.

1. People with PCOS are at higher risk of anxiety, mood swings, depression and eating disorders such as binge-eating disorder, bulimia and anorexia.
2. Not enough information is provided about PCOS at the time of its diagnosis.
3. PCOS is easier to talk about with increasing age as it is a physical health issue, while mental health issues are tougher to talk about.
4. People with PCOS are more likely to talk to loved ones than to people in their immediate surroundings, likely as family falls in the latter and menstruation is often considered taboo.
5. Diets and exercise are the most common ways to deal with PCOS, but diets may trigger EDs - intuitive eating is an option to consider.
6. Exercise and talking to loved ones helps people with PCOS cope with their mental health issues. Therapy, despite being the most professional option, remains unpopular.
7. A severe lack of awareness surrounds polycystic ovarian syndrome, as well as how much it can affect mental health.
8. Education about PCOS must begin at an earlier age.
9. No universal method exists for dealing with PCOS or the mental health issues that accompany it.
10. Research into PCOS is still extremely inadequate and must move forward.

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7. APPENDIX

1. Hirsutism: growth of extra, dark or coarse hair, primarily due to increased androgen - typically testosterone - levels
2. Insulin resistance: inability of body to respond to insulin, resulting in lowered control of blood glucose level
3. Amenorrhea: absence of periods
4. Menarche: the first time menstruation occurs
5. Progestin: synthetic form of progestogen used in hormonal birth control pills and menopausal hormone therapy
6. Hyperandrogenism: high androgen levels in person assigned female at birth
7. Anovulation: absence of ovulation

Survey form given to participants

Note: The option '1, 2, 3, 4, 5' indicates that the survey's respondent was given a statement to be rated on a linear scale of 1-5, where 1 meant the lowest rating, and 5 the highest.

Question	Options
General	
I take care of my mental health.	1, 2, 3, 4, 5
I take measures to deal with PCOS.	1, 2, 3, 4, 5
PCOS affects my daily routine.	1, 2, 3, 4, 5
PCOS affects my mental health.	1, 2, 3, 4, 5
I experience/have the following:	Depression Anxiety Mood swings Bulimia Anorexia Other (please specify)
My mental health affects the frequency of my periods. (For example, you may notice a delay due to severe stress. If you have not observed this, please skip.)	1, 2, 3, 4, 5

Age	
Age group	Below 18 18-25 25 or above
PCOS is easier to deal with as I grow older.	1, 2, 3, 4, 5
My age has played a role in how comfortable I felt with talking about PCOS.	1, 2, 3, 4, 5
My age has played a role in how comfortable I felt with talking about my mental health.	1, 2, 3, 4, 5
I wish I was taught about this when I was younger/in school.	1, 2, 3, 4, 5
Education from a young age can help people with PCOS deal with their mental health in a better way.	1, 2, 3, 4, 5
Coping methods	
Which of the following activities help you deal effectively with PCOS?	Exercise/physical activity Therapy Talking to peers/friends/family Diet/dietary supplements Other (please specify)
Which of the following activities help you deal effectively with mental health issues?	Exercise/physical activity Therapy Talking to peers/friends/family Diet/dietary supplements Other (please specify)
Medication helps me with PCOS. (If you do not take any medication, then please choose according to whether you believe it could help you.)	1, 2, 3, 4, 5
Medication helps me with my mental health. (If you do not take any medication, then please choose according to whether you believe it could help you.)	1, 2, 3, 4, 5

Family and environment	
PCOS is talked about openly in my immediate environment (family at home/friends in educational institutions).	1, 2, 3, 4, 5
Mental health is openly talked about in my immediate environment (family at home/friends at educational institution/workplace).	1, 2, 3, 4, 5
I talk about PCOS comfortably with my family/friends/peers.	1, 2, 3, 4, 5
I talk about my mental health comfortably with my family/friends/peers.	1, 2, 3, 4, 5
There is enough awareness about PCOS and its relation with mental health.	1, 2, 3, 4, 5