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# 'Am I turning into a man?' experiences of Pakistani women with PCOS

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# <u>'AM I TURNING INTO A MAN?'</u> EXPERIENCES OF PAKISTANI WOMEN WITH PCOS

This Capstone Project is submitted to the Faculty of Business Administration as partial fulfilment of Master of Science in Journalism (MSJ) degree

by

Rida e Zehra Zaidi

Supervised by **Muna Khan** Lecturer Centre for Excellence in Journalism Institute of Business Administration (IBA), Karachi

Fall Semester 2019 Institute of Business Administration (IBA), Karachi, Pakistan





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# Abstract

According to the National Institutes of Health, 20 - 25% of all regularly ovulating women have PCOS. This disorder has a range of visible symptoms including excessive weight gain, hirsutism, acne, and hair loss among others. These symptoms make it difficult for women with the syndrome to fit the femininity ideals of the society, as it demands female bodies to be slim, smart, hair less, and to have porcelain skin and regular menstrual cycles. Women with PCOS and other health problems in Pakistan spend all their lives fighting unnecessary battles. This struggle has severe impacts on their physical and mental well-being.

# 'Am I turning into a man?'

## **Experiences of Pakistani women with PCOS**

It was a cold morning in 2011 when 17-years-old Hoorain Zehra went to Pasha Clinic and Maternity Home in P.E.C.H.S, Karachi, to see a gynaecologist.

It was the first time the teenage girl had kept foot in the maternity home, after the day she was born there. She looked around the waiting area nervously and saw a number of pregnant ladies sitting there, waiting for their turn to consult the doctor. "I don't remember many details from that day but I also don't think I'll ever forget how everyone was staring at me, probably thinking what a young girl like me was doing at a gynaecologist's clinic," recalls Hoorain with a smile on her face. "It was a long time ago and back then there was no awareness about women's reproductive health, I mean it was even less than it is today. People used to think that only pregnant women could go to the gynaecologist, you don't need to go before that or if you're single or young," she said.

Hoorain's mother Haniya, who was a teacher at one of the biggest private schools in Karachi could not take the day off to take her daughter to see the doctor, so instead, the girl was accompanied by her aunt Sameera.

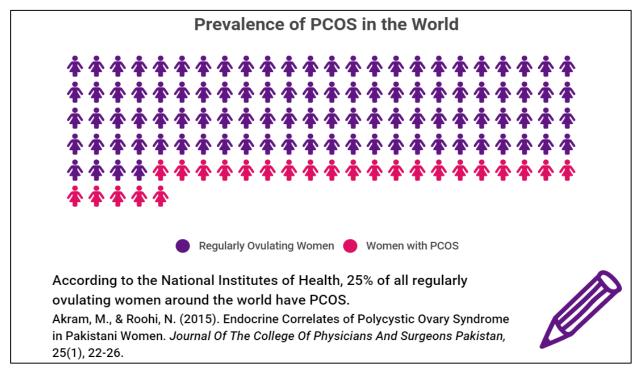
What made Hoorain go to the clinic was that she had not had her periods in two months, and it was not the first time she had missed them. She was also getting dark and coarse hair on her face, especially on her chin which caused immense worry for both her and her mother. "I couldn't answer any of the questions the gynaecologist was asking me, I felt so shy talking about my facial hair. That was something I hated actually. So, when she kept probing and asking for details, I felt so weird and uncomfortable. Talking about something kind of private even though I had to talk to a lady about it was still very weird. My *phuppo* was answering all the questions for me," she said.

The teenage girl has since grown up into a confident 27-years-old woman. She has requested to maintain her anonymity, Hoorain is not her real name.

After the consultation, an ultrasound, and a few blood tests, the gynaecologist diagnosed Hoorain with Polycystic Ovary Syndrome (PCOS).

Dr. Nehzat Samana, who is a Resident Medical Officer at a private hospital in Karachi, describes PCOS as a serious genetic, metabolic, hormonal, and reproductive syndrome. "Its first few signs include irregular menstrual cycles, if it's regular it tends to be more than 35 days long. Others include no periods at all, hormonal imbalance, male pattern hair growth like on the face, chest, and back, weight gain, acne, hair loss from scalp and thinning of hair," she said.

Dr. Nehzat believes that PCOS should not be taken lightly. "It can actually be lifethreatening if left untreated, as it can lead to cardiovascular disease, type 2 diabetes mellitus, stroke, and Demetrius Cancer."



According to the National Institutes of Health, 20 - 25% of all regularly ovulating women have PCOS. The prevalence of the hormonal disorder is much higher in South Asian women, especially in Pakistani women, as compared to Western women, with the rate being 52% and 25% respectively. (Akram & Roohi, 2015)

"When diagnosed with PCOS, women react very emotionally. They take that they must go on lifelong treatment and that it's an incurable disease. While I don't remember any particular patient, women usually get very stressed out, I mean you can see it on their faces, and a lot of patients go into depression but medical counseling helps cope with these things," said Dr. Samana.

Being diagnosed with PCOS came as a "big shock" for Hoorain as well. Mostly, because she did not know what it was, and it sounded scary to her. "Sameera *phuppo* herself studied medicine so she knew what it was but I didn't obviously, and the gynaecologist didn't even explain it to me, she just talked to my *phuppo* and then afterward I asked her what it was and she told me that it's a cyst in my ovary," said Hoorain. Not knowing what a cyst was at the young age of 17, she asked her aunt to explain it to her in further detail. "It's kind of like a tiny tumor thing, my *phuppo* had said and that freaked me out because obviously who wouldn't get freaked out about that," she continued.

Finding out that all the changes happening in her body was not just because of puberty but also because of PCOS, gave Hoorain some clarity. However, not knowing anyone else who was also going through the same thing made it tough for her to accept herself. "I didn't know if anyone else had it so whatever I went through I talked to my mother about it and other than that I coped with it by reading stories about other women on the internet. It helped me and it comforted me. No one else was going through it besides me at that point in my life or at least that's what I thought. And even if they were, people were like very hush-hush about it as it's kind of a taboo," said Hoorain.

She also recalls getting scolded by her mother for saying the word 'ovary'. "My mother had looked at me with disbelief in her eyes and told me that these kinds of words shouldn't be coming out of a young girl's mouth," she said. Not only was Hoorain not allowed to say the O word but she was also asked by the elder women in her family to take the medicines in secret. "My entire family was so hushed about it and that left me so confused. Even when I was taking medicines, it was like ohhhh she just needs them, and nobody asked why, and nobody answered why."

This behaviour by her family made Hoorain, who was already an introvert, retreat into herself even more. It made it difficult for her to communicate with others, she thought that no one would understand her feelings let alone console her. "Instead of opening up to others, I started talking to myself. I know this might sound funny and weird but I had watched a video on YouTube about intrapersonal communication and how it can help you build yourself up, so I decided to take up that practice," she said.

Hoorain would stand in front of a mirror and tell herself that she was beautiful and that she was a woman. "My self-esteem was gone at that point. So, I consoled myself and told myself that it'll all go away eventually, you just have to keep taking my medicine. you're a woman, and you're beautiful no matter what stupid thoughts enter your brain. You're beautiful and don't think less of yourself because of this, this doesn't define you," she told herself every night.

## **Mental Health and PCOS**

According to a study published by the National Institutes of Health, PCOS not only has long term effects on the patients' physical health but it also impacts their mental well-being. Some psychological consequences of the syndrome are anxiety and depression. While a number of

studies have tried to understand anxiety and depression in PCOS women, not much research has been done on how it impacts self-esteem and body image perception in women.

After long hours of searching, one comparative study from 2013 was found in which researchers have attempted to measure self-confidence in women with and without PCOS. The study included 400 women from Tehran, Iran, 100 with and 300 without PCOS. The obtained results were shocking, as only 6.7% of women without PCOS scored low on self-confidence while *all* the women with PCOS scored low. (Amini, Valian, Avvalshahar & Montaeri, 2014) According to this study, PCOS can cause an increase in the anxiety levels of women by decreasing self-worth and body image perception. Moreover, changes in physical attractiveness lower self-confidence, along with it goes motivation, emotions, and decision-making skills. Increased risk of interfertility and sterility also causes a change in the patients' body image. While this study focused on Iran, it can also be applied to women in Pakistan.

Mahil Tufail, a clinical psychologist from Karachi explains that PCOS is a hormonal disturbance within the body. With it comes; insulin resistance, PMS, delayed periods, body image issues, exhaustion, frustration, side effects from medication, more propensity to get anxious, acne, and a host of other problems.

"The way it affects body image is that you can get acne, you start losing hair and these things are very important, especially for young girls as they are growing up to sort of look at their peers, to look at social media and celebrities, the perfect body image or the perfect skin. Not being able to conform to that image leads to a lot of anxiety and that leads to depression and sadness among younger girls," she said.

Tufail, who is a graduate of the Royal Holloway University of London, says that selfworth gets a major hit in women with the syndrome. They can also find it difficult to fit the femininity ideals of our society. "Our society demands that you have to be white, your skin has to be clear, your hair has to be long, shiny, black, and thick. There is a long list of 'has to be's and 'should be's, where every woman is struggling. Obviously, for women who have PCOS, it's much harder. There is a biological hurdle for PCOS patients, but I believe that femininity ideals harm everyone equally," says the psychologist.

One of the visible symptoms of PCOS is Hirsutism, which means that women start to get excessive growth of hair in a male-like pattern, such as on their face, chest, and back. This makes it difficult for them to an intelligible part of society. According to a study, women with these symptoms felt "freakish, abnormal and not proper women." (Snyder, 2006)

This is like what Hoorain experienced when she was diagnosed with the syndrome. "Coming back from the doctor's, I was in shock the whole time and I remember getting depressed as I was also fighting with depression at that time and it was really hard to control it. Being a teenager and hitting puberty and getting this weird hormonal disease, it all just piled up and I was hating myself. I wondered what I did to deserve this. I also felt scared, and questioned, am I turning into a man?" she said.

This thought about her 'turning into a man' had not come to Hoorain out of nowhere. Around the same time, she had found out about her having PCOS, a 17-years-old girl in her apartment complex came out as a trans man. "It was a girl I knew and then she got surgery to turn into a boy. It freaked me out because I was also 17 and getting facial hair. It was really hard, and I forced myself to stand in front of a mirror and tell myself you're a woman and you're beautiful," said Hoorain

"When you have facial hair, it's not easy. People make fun of you because it and I just wanted to hide. I didn't want to talk to anyone, I didn't want to meet anyone, and I got conscious every time anyone would come close to me and talk to me. I always kept on wondering can they see it, can they see my facial hair, what are they thinking, I also got anxiety because of it," recalls Hoorain. She has had PCOS for more than a decade, but whenever her period date gets near, she starts feeling anxious.

Women with PCOS go through a constant internal struggle. They must stay on top of what they are doing and what they are eating. It is already a difficult life to lead and according to Hoorain, "other people make it worse." "Nobody understands the fact that women come in all shapes and sizes. People only think that if someone has weight issues it just means they eat a lot even though as far as I have seen, those women who are struggling with weight are women who have PCOS or other forms of hormonal imbalances, not because they eat a lot. Then they get bullied because of it and people are like *kam khaya karo na tum ziada khati ho na isliye weight gain kar rahi ho*. I only have two meals a day, which is not enough to make me obese, yet here we are," she said.

PCOS does not only affect the patient's life but also of those around them. Hoorain's mother, Haniya says that she was extremely worried about her daughter's facial hair and now she feels guilty for reacting extremely.

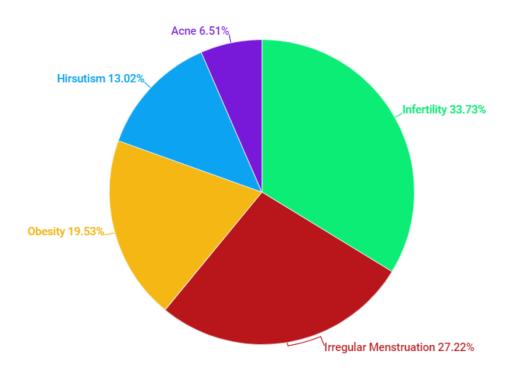
Recalling Hoorain's ninth-grade party she said that she didn't want Hoorain to feel different from other girls so she dressed her up and put makeup on her face, but that made the hair on her face stand out even more. "I worried about her constantly. I didn't want her friends to make fun of her because of it so I decided to take her to the doctor for proper treatment," she said. Every time Haniya went to the beauty salon, she noticed mothers accompanying their daughters and getting their faces waxed. "I didn't want Hoorain to go through that painful

process, but I had no choice. The ladies at the salon had convinced me that frequent waxing would lessen the hair growth," she said.

Haniya says she feels sorry for her obsessive behaviour. "I think my extreme reaction might have ruined my daughter's childhood," she said. Hoorain loved to eat cakes and drink juices, which her mother put a restriction on because of the doctor's suggestion to cut down her sugar intake. "I wanted what was best for her, what mother wouldn't want her child to eat and drink as she liked but my worries got the best of me and I became extra controlling. I feel very bad about it now," said Haniya.

#### **Dealing with the Risk of Infertility with PCOS**

In the study conducted by Snyder, 12 female participants were interviewed. The purpose of the research was to gauge what women with the syndrome think about their lives. The findings described seven different experiences that were common in all the participants including wanting to be normal, gaining control, letting go of guilt, dealing with it, acknowledging the impact on femininity, and identifying differences. The first thing the participants showed was that they recognize not all women with PCOS have the same experiences. The signs and symptoms with which it manifests vary significantly in everyone. (Snyder, 2)



## Primary Concerns of Women with PCOS

Zafar, U., Memon, Z., Moin, K., Agha, S., Hassan, J., & Zehra, D. (2019). Prevalence of PCOS with Associated Symptoms and Complications at Tertiary Care Hospital of Karachi. *Journal Of Advances In Medicine And Medical Research*, 1-9.

Tahira Ali, a 28-years-old married woman, who is currently pursuing her master's degree in computer science says that her biggest worry with having PCOS was that she would not be able to conceive. Tahira had always loved children, even if she could not voice her concern to others, it bothered her immensely.

Just like Hoorain, Tahira also went to the doctor at the age of 17 because of irregular periods, and cramps that felt like "someone was trying to cut her gut out." "Confusion and fear would be the words to describe my feelings at the time of the diagnosis. I didn't know what it meant for my fertility as no one would talk about it," she said.

The first thing Tahira did after coming back from the doctor's clinic was to look up different forums where people ask questions to doctors and other women. She found out through these groups that it is not as bad as one might think it is. "It's not like it's going to ruin your life, or you won't ever be able to have kids, I told myself. So that day and days after that I kept doing my research and I found out that a lot of women have this problem, it's not just me. I read stories about how other women dealt with it, and how it impacted their fertility and

femininity but after all, they were able to cope with it by taking on a balanced diet and working out. This gave me immense relief and I started feeling a lot better than I did before," said Tahira. After dealing with it alone for many years, and only confiding in her mother and younger sister occasionally, Tahira was fortunate to find a husband, Hassnain Ali, who fully supports her. While Hassnain understood Tahira's condition, his family was another story. The couple lives in a joint family system which includes Hassnain's parents, his brother and his family, and his uncle's family. "One of the biggest challenges that we faced after just getting married was going to the doctors. My husband knew everything, but my in-laws didn't. Living in a house full of people with different mindsets, things could easily go wrong if someone found out where we were going. In our society, the girl starts getting blamed for being infertile and what not. To avoid all of that, my husband and I had to lie to everyone about going to the doctors during the time I was getting my treatment. It's one of the hardest things we've had to do," said Tahira. Despite her misconception that she would not be able to become a mother, Tahira received regular treatment, and one day the couple got the news that they would soon become parents. Hassnain and Tahira had a baby boy, who is now 3 years old. "All my misunderstandings went away the day I conceived. I used to spend so much time on the internet looking for answers on whether I would be able to conceive or not and I'm sure there are a lot of girls out there going through the same, but they'll inshallah also get their answers the way I got in the form of my baby," said Tahira.

Research that focuses on fertility concerns and sexual behaviour in adolescent girls with PCOS, states that young women with the syndrome are more concerned (3.4 times) about their ability to become pregnant than their healthy counterparts. This concern about future fertility significantly reduces their overall quality of life. (Trent, Rich, Austin & Gordon, 2003)

While discussing this study, the clinical psychologist Tufail said that "9 out of 10 times when a woman goes to the doctor regarding a PCOS diagnosis or to an endocrinologist is because she has infertility issues, before which it is not likely to be diagnosed. Women's self-worth is largely tied to them being mothers and that if they cannot be mothers, they think that they are somehow not useful or that they are not fulfilling their function to society."

In Tufail's opinion, this is strongly tied to traditional and cultural gender roles in Pakistan. "Now that we are in the 21<sup>st</sup> century, women are in dynamic roles; they are mothers, yes but they are also working, they are going beyond the age of 30 without being married, they are also pursuing higher education and they are also adopting children. So, I mean there are a wide variety of roles that women are fulfilling and that traditional roles of motherhood are no longer commonplace in this century," said Tufail.

#### Absence of Conversation from Mainstream – And the Shift

Both Hoorain and Tahira faced a similar problem at the time of their diagnosis. They were clueless about what PCOS was. Their first resort to learn about it was the internet. This demonstrates the absence of conversation about the syndrome from the mainstream.

Why don't we talk about PCOS, especially when many Pakistani women are affected by it?

A professor of women and gender studies, Afiya Zia answers this question. Building on her experience in the field as a consultant where she monitors, evaluates, and give strategic advice and recommendations to programs related to women's health, empowerment, education, and violence, she says that Pakistani culture is fearful of women's bodies. "We consider it to be a taboo subject and the threat to men is that if we gain a lot of knowledge about this it will be used for sexual relations," she explained.

Now, the fact is sexual relations and sexual abuse does take place and if we do not inform people about it, we cannot prevent the abuse from taking part. The threat that the body will be used for pleasure, makes it such that we end up not even protecting it. We rely on a lot of mythmaking and that is why misinformation and fake information circulates without any regulation, be it for PCOS or any other women related problem.

Communication about women's reproductive health is culturally constrained in our country. Just like Hoorain was told to stay secretive about her diagnosis of PCOS, girls are also taught to remain silent about menstruation. This secrecy promotes views that menstruation is dirty and gross, as a result, it is seen as a negative event that leads to feelings of shame and embarrassment in women.

Stigmatization of periods is also perpetuated via social media. In 2015, poet Rupi Kaur posted a picture on her Instagram that showed a visible menstrual bloodstain at the back of her pants. Receiving backlash from viewers, the photo was deleted from the social media platform twice as it allegedly violated the app's norms. Since Kaur's post, a lot of celebrities have taken to social media to talk about this "taboo" topic of women's reproductive health. Bollywood actress, Sonam Kapoor revealed in September that she has been suffering from PCOS since the age of 14. Similarly, Hollywood actress, Keke Palmer posted a no-makeup selfie on her Instagram and wrote a caption about her life-long struggle with acne and finding out that she has PCOS.

One of the top Instagram bloggers of Pakistan, Hemayal ran an awareness campaign about the syndrome during September, which is the official PCOS awareness month. Taking this into account, it can be said that there has been a shift from complete secrecy and silence to opening up and talking about women's reproductive health on a mainstream level.

This shift can be attributed to agitating factors such as the Aurat March and women-oriented social media groups.

Feminist activism in Pakistan has been reborn and this time, woman are adamant about breaking the silences and barriers that have been imposed on them by patriarchy, in the name of culture and religion. Women are now expressing their ideas on social issues, such as child marriage, women's health, inheritance, polygamy, the right to education more freely than before.

The doors to dialogue are gradually opening up, and one of the reasons for this could be the presence of women-oriented groups on social media. According to Brene Brown, an American Professor, women become resilient to shame when they share their stories and experiences with other women. This helps them create a connection with a community of people who are going through the same struggle. (Brown, 2007)

This sense of community and connection can be seen in Facebook groups, such as Soul Sister's Pakistan and many others. These platforms allow Pakistani women, from all over the world, to share their problems, ask for advice, and empathize with each other. A recognition of collective vulnerability helps them realize that they are not alone.

Reading about other women's experiences with PCOS also helped Hoorain and Tahira during their journeys with the syndrome. In fact, it became one of their greatest support systems.

## **Understanding and Supporting Women with PCOS**

A qualitative study in an ethnically diverse group from the UK was conducted in 2017 to understand women's experiences of living with PCOS. The purpose of the study was to broaden the scope of current knowledge regarding support needs. Through unstructured interviews with the participants, the researchers found out that emotional support was the most important. However, the amount of support the women received from family members varied greatly. Some women said that they were embarrassed about discussing their condition with family members, and some said that the support they were offered was limited by poor understanding. (Hadjiconstantinou et al., 2016)

This is evident in the cases of both Hoorain and Tahira. Even though Hoorain's aunt took her to the doctor's, she still felt closed off by her family. They put restrictions on her to

not speak about the syndrome in front of others and to take the medicines in secret, so the man in her family would not find out.

Hoorain says she was able to find emotional support from her friends in university later in life. "When I was diagnosed with PCOS, I would always worry about it. The constant worry subsided when I found out that other women were also going through these symptoms. Three of my friends who were very vocal about their problems shared their experiences with facial hair growth. When they started talking about it, I also became vocal about my issue. Finding out that other women, who were close to me were also going through the same thing helped me a lot. I learned how to deal with it with a positive mindset. So later, it became a part of me, and I got kind of comfortable," said Hoorain.

On the other hand, Tahira did not have to go through any major problems. Before marriage, she lived in a female dominant household, so it was easy for her to discussed PCOS related things with her mother and sister. Later, she got married to a man who was supportive of her. "I've found a strong support system in my husband. He helps me with all kinds of challenges I face in my life. He uplifts me, motivates me, and pushes me to be a better person, to live a healthy life. He found out about it at the very beginning of our marriage, when I missed my periods but he never made a fuss about it and instead took me to a doctor's and read up on the syndrome so that he understood clearly," said Tahira.

Even though it has been years since Tahira has been dealing with PCOS, she still cannot talk openly about it with people besides her mother, her sister, or her husband. When women in her in-laws discuss their pregnancies and other details, Tahira says that she tends to step away from those conversations as she feels that talking about her condition would make the other women think less of her. "They would take it as my weakness or something, they wouldn't understand even though they are women," she said.

The second type of support needs the study mentions is from health care providers. Most of the women reported feeling better with having a specialist PCOS support nurse.

Tufail also believes that the role of a doctor is extremely important in making the patient feel a certain way about their illness, both at the time of diagnosis and after. "Not everyone comes from medical or psychological backgrounds and not everyone knows their conditions, in the sense that how many people are affected by PCOs and how pervasive this condition is and that it's most commonly found in a lot of women in Pakistan. A doctor or a clinician needs to make their patients understand the treatment plans and the host of lifestyle changes that are required to control the condition. There are many other things too, not just body image issues

and propensity to depression and anxiety, but also infertility issues and how it could impact relationships and every part of the patient's life," she said.

Tufail also believes that doctors should be able to psycho-educate their patients. Doctors should also let patients know they can always get support in therapy if they need to. "It is very important, it is imperial for a doctor to psycho-educate the patient fully and come up with a holistic treatment plan," she said.

#### **Creating Awareness About the Syndrome**

Doctors play a significant role in creating awareness about women's health. Speaking about the current awareness creating mechanism in our society, the professor at the University of Toronto Zia says, "we rely on ethnic communities to deliver to their people, give charity and provide health treatments to their people but nobody thinks holistically about women's bodies and how to educate us about our bodies and how to deal with different kinds of hormonal changes."

"Nobody talks about hormones, many of these words don't even have an Urdu translation to them so the linkage is hard to make. I want to argue that lady health workers' knowledge base should be expanded, why should they be limited to women's reproductive process, conception cycles, or vaccines, you should give them holistic training so that they can deal with various issues like hormonal issues. They don't have to be doctors to do that, they can hold training sessions about the different stages a women's body goes through during her lifetime. This is not taught in schools, neither is there a radio program about it nor does the health sector take responsibility," she continued.

Whether it is in education or health, the issue is not about demand, nor is it about cultural obstacles or interference of 'molvis', the issue is of supply. The shortage of the supply of knowledge becomes a huge hindrance when attempting to create awareness. As soon as the ones with authority understand that, be it the state or non-profit organizations, many cultural and other barriers will fall. Moreover, a subsidiary market of supply will open up, a subsidiary way of thinking will open up, word of mouth will happen, and the use of social media will happen. All the authorities have to do is make the strategy properly, build trust, and make sure that everything is of quality, and the people who are administering these things are held accountable. "If money is spent properly on a campaign, it will show good results," said Zia. Speaking about her experience with evaluating communication strategies, Zia says, "For any knowledge spreading program, many obstacles come in the way even if it is delivered in a great

way. If the community is not prepared for it, the program will not be successful, so the community's take is very important."

Other obstacles include the absence of the right intermediaries, for example, if the administrator has no connection to the town, neither does a donor nor the government then they will have to go through local intermediaries which are middle women, or men, or social mobilizers. Their role becomes very important, however, the fact that their knowledge and expertise are limited causes a problem.

"To overcome these obstacles, you need a series of experts on every level. You need people who have a social and cultural grasp on things. You need programs to be regulated otherwise, they won't be successful. There have also been experiments where women talk alone. However, I have seen that mixed sessions have been quite successful, as trainers now understand how to include men in the conversation as well. The goal is to help them become a merited team that can stand up against pressures from the family. They can remove their interference by making a pact between themselves about family planning or the woman's health," said Zia.

Some of the biggest obstacles remain distances from facilities and distances from knowledge. Imaginative and good ways to spread knowledge are required to overcome them. The government of Bangladesh and Plan International, which is a humanitarian organization, came up with an app that helped the matchmakers and marriage registrars stop over 3,700 child marriages in the country in 6 months. The app made it possible for them to establish the true age of the bride and groom. Similarly, the application of COVID-19 created by the Government of Pakistan has been a huge success.

Women with PCOS and other health problems in Pakistan spend all their lives fighting unnecessary battles. This struggle has severe impacts on their physical and mental well-being. If entire series of applications are made on different aspects including women's health, and other awareness campaigns are also run diligently, it can result in significant changes in the lives of these women and consequently, in the country.

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