Experience and knowledge of polycystic ovary syndrome (pcos) among pcos-diagnosed...

Parts of the World, Asia

Qualitative Results of Thematic Analysis

PCOS diagnosis experience

The respondents reported to be dissatisfied with their PCOS diagnosis experience. For the majority of the respondents, diagnosis of PCOS required changing more than one healthcare provider within a year. Dissatisfaction was associated with the perceived lack of explanation or information about PCOS and its management. One respondent expressed during her interview:

"…I have been suffering for a long time, I cannot even remember how long. Every year I was changing doctors, taking tests worth of thousands of Taka (Bangladeshi currency). When I was finally diagnosed by a gynecologist, she explained absolutely nothing and gave me medicine which I came to know from pharmacists is used for diabetes. Why would someone give a person of 19 years of age a diabetes medicine when the reports were clearly showing I did not have diabetes? Well, how could I tell? My doctor informed me of nothing…"

Many of the women lacked knowledge of PCOS and its symptoms prior to their diagnosis which contributed to delayed diagnosis and medical management, supporting the findings in Table 3 where 84% (n= 21) reported knowing nothing about PCOS before diagnosis. In the words of one respondent:

"…I waited for long before visiting my doctor (for my symptoms). It never occurred to me that perhaps something is wrong with my body. I never

heard anything of such kind, otherwise, I would have gone to the doctor faster…”

The unmarried respondents explained that irregular menstruation or overweight was the main reason for consulting a healthcare provider. Young women experiencing irregular menstruation in Bangladesh have often been told that menstruation irregularity would “ go away” with age or after marriage, or that conception will help improve their problem and remedy their PCOS.

“…I was a second year bachelor’s student (when I was diagnosed with PCOS). I was not planning to get married very soon, but my doctor emphasized that I should get married very soon and conceive. This is the most important solution. My parents were convinced after hearing that from my doctor and they were constantly pressuring me about that. They still do…”.

The married respondents shared that they primarily went to their healthcare providers when they were being unable to conceive. Their experience was perceived by the respondents as feeling frightened and uncertain about their future after learning of their PCOS diagnosis. Much of the feeling of uncertainty was associated with the “ inability of becoming pregnant” or “ possibility of being infertile,” as described by one respondent:

“…I was worried, afraid… I did not know what to expect from [PCOS]. The first thing that came to my mind was if I would be able to become a mother

or not? My mother was at the doctor's office that day. She expressed the same concern to the doctor…"

Feeling " uncertainty about the future" for the respondents was increased when their family members also expressed almost similar worries related to their health and uncertainty of conceiving. Respondents repeatedly expressed that their families, especially their mothers, were about their daughters' ability to become pregnant, as PCOS was not commonly discussed with the women's fathers.

Knowledge of PCOS

Many of the women who had been diagnosed reported that they did not know anything about PCOS before being diagnosed and that they continued to have limited knowledge about their condition even after being diagnosed with PCOS, as shown in Table 3. The issue of limited knowledge by PCOS-diagnosed Bangladeshi women was reflected by one respondent's expression:

"…I knew nothing about PCOS before. I know nothing about PCOS now. My doctor just told me once that I have PCOS, suggested me to lose weight but did not guide me through it. I am maintaining my usual life, trying to eat less. That is all…".

Moreover, the respondents suggested that as they did not get an explanation of how PCOS affected other aspects of their lives including emotional turbulence that may be associated with PCOS and can be managed. According to one respondent:

"…I knew that I was going through some emotional changes. Due to lack of awareness, I was never able to relate my emotional disturbance to PCOS. I always thought it was due to all of the things going on in my life. I realized (that PCOS and emotional turbulence) could be related when I took the survey questionnaire for this research which made me Google the symptoms of PCOS. I was surprised to see that I could relate most of the (emotional) conditions I experienced…"

Role of religion and culture in relation to PCOS

Respondents perceived there to be a strong relationship between Bangladeshi culture, rather than religion, and the lack of knowledge of PCOS. Respondents identified that women's health is regarded as a " secret issue" in the Bangladeshi culture and that the women tended not to share their health issues with others, particularly males. As Table 3 shows, women preferred to discuss PCOS with females than with males, which was explained:

"…We never do that. We have been taught throughout our lives that this can never be done; this should never be done. We should keep our menstruation to ourselves, we should keep our pains to ourselves. If someone knows [about it], it is a disgrace for us…".

The women expressed that their health problems had been minimized or dismissed by their healthcare providers and there was an overall lack of discussion about women's health issues, even when the women sought information from professionals. The women had been informed that their PCOS would be " corrected with age and after marriage." This quest for

information and dismissive medical response was reflected in the expression of one of the respondents:

"...My mother changed six doctors [for my condition], all of them suggested that I will be alright when I will grow up, when I will get married, and finally when I will have a baby...".

Another issued identified by the respondents was that there was a cultural component; Bangladeshi women face social pressure from their families to get married, conceive, and give birth. Healthcare providers perpetuate similar attitudes as the women heard messages from them suggesting that getting married and conceiving were the " cure" for PCOS and other gynecological problems. Respondents reported that the healthcare providers played a crucial role in putting pressure on the PCOS-diagnosed women to get married and conceive:

"...The common suggestion a Bangladeshi woman gets from her gynecologist is to get married and have babies. They do not, I should rather say cannot, consider the idea that a woman perhaps does not want to get married, or wants to get married but does not wish to reproduce. If a woman says anything like that in Bangladesh, she is an anomaly. Pretty soon she is going to experience societal pressure and be ostracized if she does not get married and produce a child before her age 'expires...".

Respondents reported that cultural factors such as the importance of getting married and having children in combination with limited discussion of

women's health and PCOS has associated this condition with stigma and shame. One respondent expressed:

"...You cannot talk to anyone (about your condition), you cannot inform anyone (that you have PCOS or any other gynecological diseases). I can share a horrifying experience. One of my cousins, from the maternal side, mentioned to her would-be in-laws that she has menstrual irregularities. As a consequence of her honesty, her future possible in-laws called off the wedding. She had to go through severe shaming because of that. Now tell me, who would talk about (women's) health if society treated you that way?"

Discussion

This research study focused on understanding the experience and knowledge of PCOS among PCOS-diagnosed Bangladeshi women. Additionally, this study examined the perceived role of culture in the experience of having PCOS among the respondents. Overall findings are derived from three themes that emerged from the data reflecting the experiences of the respondents. The first theme indicated that the PCOS diagnosis experience of Bangladeshi women is overall negative with the women expressing dissatisfaction, which was also found by other researchers [6, 8]. Women had to visit multiple healthcare providers over the course of multiple years to finally be diagnosed with PCOS. This challenge to and dissatisfaction with PCOS diagnosis has been noted in previous studies [6, 8]. Changing multiple healthcare providers is associated with the lack of cooperation from healthcare providers and their lack of information and knowledge [5]. Independent of their age, education level, profession, and

geographic location, this response was shared by most of the respondents. This indicates a need for improvement of the resources and service delivery related to PCOS in Bangladesh [5, 6, 7, 8].

Lack of knowledge among the healthcare providers [8] often resulted in suggesting supposed remedies of PCOS that were not evidence-based such as getting married and conceiving. It is important to give accurate information that PCOS is incurable but is manageable with various treatment options. The lack of knowledge on PCOS among the healthcare providers has been found to result in women's dissatisfaction with their PCOS diagnosis experience [8]. Women desire to be more informed by their healthcare providers of the causes, symptoms, and treatment options of PCOS [5]. Lack of information about PCOS among PCOS-diagnosed women can cause increased concern and uncertainty about their future [7, 8].

Having limited knowledge of PCOS by the diagnosed women has been found to be a common issue around the world [7]. In Bangladesh, important contributing factors regarding the limited knowledge on PCOS include lack of overall health knowledge, lack of proper and accurate PCOS information, lack of support by the healthcare providers in obtaining information, and the consideration of women's health issues as secret topics that should not be discussed [2, 5, 7, 8, 10, 11, 19, 21].

The most common health concern expressed by the PCOS-diagnosed women was related to issues of infertility or subfertility associated with PCOS [2]. This concern of problems with fertility may overshadow other aspects related

to PCOS. Married respondents reported seeking treatment for their " infertility" problem [2] while not reporting concerns related to other physical consequences of PCOS. Healthcare providers should educate PCOS-diagnosed women about other major health concerns related to PCOS such as the increased risk of type 2 diabetes, cardiovascular disease, and endometrial cancers [2, 11, 12].

Information availability has a crucial role to play in improving access to knowledge about PCOS among Bangladeshi people [2, 4, 5, 6, 7, 8, 11, 19, 22]. The respondents' identification of the Internet as a source of information on PCOS has also been found by other researchers [11, 19, 22]. However, culturally sensitive and inclusive information would benefit Bangladeshi women such as suggestions for dietary modifications and exercise such as strength training [20]. For Bangladeshi women, strength training may be discouraged as too masculine. Hence, it is highly recommended that healthcare providers and researchers culturally adapt the information on PCOS management for acceptability and availability among Bangladeshi women [2, 4, 5, 6, 7, 8].

The respondents have associated culture as an influencing factor in PCOS knowledge among PCOS-diagnosed Bangladeshi women and healthcare providers [5, 7, 8]. The respondents who thought Bangladeshi culture influenced the knowledge of PCOS among Bangladeshi women identified differed reasons. While not stated by the women, a common attitude in the Bangladeshi society is the perception that any disease is negative [6, 13, 14]. There is a risk of gossip regarding uncommon conditions such as

infertility [13, 14]. Yet, women's health is generally avoided as informative discussion [7, 8]. Some of the respondents reported discussing PCOS with family and friends, although with preference of discussing their condition only with females. Hence, males are left outside of the conversation on women's health which may limit the dissemination of knowledge on PCOS [7, 8].

Bangladeshi women may experience pressure related to fertility and childbirth [6, 13, 14, 17, 18, 23]. There is a cultural " standard" that women need to get married and give birth to children [6, 13, 14, 17, 18, 23]. Since PCOS is associated with infertility, subfertility, and compilations in pregnancy, it is difficult for women to discuss PCOS with people as they may be " stigmatized." All of these factors in conjunction has created an environment where women's health in general and PCOS in particular, is not discussed which results into a limited knowledge on PCOS among PCOS diagnosed Bangladeshi women [13, 14].

Finally, to increase the knowledge on PCOS it is important to promote PCOS education and public health interventions. Programs to raise awareness of PCOS is crucial as it is evident from the research that even the PCOS-diagnosed women and their families lack PCOS knowledge. Public health awareness education of PCOS should involve various stakeholders and agencies to ensure a comprehensive program including the Government of Bangladesh, researchers, healthcare providers, public health practitioners, and the PCOS diagnosed persons. Moreover, the incorporation of men in the

conversation can help reduce the stigma attached to PCOS and other women’s health problems in Bangladesh.

Limitations of the research include that there is a possibility of selection bias recruitment was done through online methods and snowball sampling among women who have Internet access. Likewise, the questionnaire was distributed via the Internet, hence, only women with access to the Internet could participate, thereby preventing women living in remote rural areas from participation as demonstrated by the high proportion of respondents from urban areas. Despite these limitations, this is the first research study conducted on PCOS-diagnosed Bangladeshi women to understand their knowledge and experience with PCOS.

Findings from this research can inform further research and the development of programs regarding PCOS among Bangladeshi women. Based on the findings, it is recommended that healthcare providers and public health researchers develop culturally appropriate and effective methods to increase the knowledge and awareness of PCOS among the people of Bangladesh, to eliminate the stigma attached to PCOS, to augment the knowledge and training of healthcare providers regarding resources for managing PCOS, and to avail information and resources regarding PCOS to women and their families in Bangladesh.

Conclusion

PCOS is a highly complex health issue experienced by women of reproductive age worldwide. Although clinical research studies have been conducted on PCOS in Bangladeshi women, there is a need for an expanded

focus on the public health aspect of PCOS. Findings from this qualitative research study identified three themes: PCOS diagnosis experience, PCOS knowledge, and role of religion and culture in relation to PCOS. The first theme pointed to dissatisfaction among PCOS-diagnosed women in Bangladesh with their PCOS diagnosis experience. According to the second theme, the diagnosed women lacked knowledge of PCOS, received limited information from their healthcare providers, and felt increased pressure and concern about getting married and having children. The third theme presented a cultural perspective, that women's health is a generally avoided topic of discussion in Bangladesh which further limits women's knowledge of PCOS and may contribute to the stigmatization of the condition and other women's health problems. To work toward addressing these issues, it is important for a comprehensive public health approach to be initiated to raise the awareness and educate the public about PCOS in Bangladesh.