

Remote assessment and reinforcement of patient awareness of role of lifestyle modification and treatment adherence in polycystic ovary syndrome using an online video based educational module

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Abstract

Objective: To evaluate the role of an online, video-based, structured, educational module in increasing awareness in women with polycystic ovary syndrome (PCOS).

Material and Methods: Patients with PCOS were assessed for baseline awareness about PCOS, quantified as “awareness score”, using a validated questionnaire. Topics assessed included factual and conceptual knowledge of the disease and awareness of behaviour-related lifestyle modification and therapy compliance in PCOS. An educational video module was shown to the participants which covered normal menstrual physiology, symptomatology, pathophysiology and natural history of PCOS, a comparative animation of healthy versus unhealthy lifestyle, indications of pharmacological intervention, and role of treatment adherence. The questionnaire was re-administered after exposure to the educational module, and effectiveness of the teaching method was evaluated by comparing pre and post test scores.

Results: The total number of subjects was 41. Baseline knowledge was “fair” in 17.1%, “moderate” in 48.8% and “good” in 34.1%. Significant increase in awareness scores was noted among participants regarding PCOS after exposure to the learning module from 15.09 ± 4.31 to 18.60 ± 3.85 ($p < 0.00001$) with a large effect size (Cohen’s $d = 0.85$). Most (48.8%) of the respondents had baseline awareness in the “moderate” range (scores between; 11-17) whereas post intervention scores improved to the “good” category for 63.4% of the women.

Conclusion: The educational module was effective in significantly increasing knowledge about PCOS. Patient education is likely to help reinforce the message about lifestyle modification and continued compliance and may aid in promoting a patient-driven healthcare model in PCOS. (J Turk Ger Gynecol Assoc 2022; 23: 1-7)

Keywords: PCOS, knowledge, awareness, learning module, healthcare

Received: 30 September, 2021 **Accepted:** 23 December, 2021

Introduction

Traditional health care delivery has been evolving into a more collaborative and co-care model, wherein the patient is expected to take more responsibility for self-care and to actively participate in clinical decision making (1). Success of such a patient-centred health care model relies on the active engagement of patients as autonomous individuals who understand the full bio-psychosocial picture of their

diagnosis, from their present physical and emotional needs to future health risks. Equipping women with accurate information tailored to their present condition is important as it improves their participation in treatment planning and breaks a perpetuating cycle of misinformation and poor health outcomes. This is especially instrumental in the treatment of chronic disorders, such as polycystic ovary syndrome (PCOS), where the lifestyle interventions are central to



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Journal of the Turkish-German Gynecological Association published by Galenos Publishing House.

DOI: [10.4274/jtgga.galenos.2021.2021-9-29](https://doi.org/10.4274/jtgga.galenos.2021.2021-9-29)

management, and therefore patient education and motivation for behavioural change as a part of initial therapy, right at the time of diagnosis, is crucial.

PCOS is a common disorder affecting 6-15% of women of reproductive age and is associated with risk of multisystem comorbidities, such as obesity, infertility, diabetes mellitus, dyslipidemia, hypertension, sleep apnea, future risk of endometrial cancer, depression, and impaired quality of life (2-6). Receiving a diagnosis of PCOS represents an opportunity to motivate women to take sustainable steps towards prevention of complications, yet the provision of relevant information by the health care providers about the role of lifestyle management and medical therapy on potential long-term consequences of PCOS is not satisfactory (7,8).

A typical patient with PCOS is an adolescent or a young woman. In addition, there may be a lack of reproductive health education in school, as comprehensive sexual and reproductive health education is not a part of the curriculum in most schools around the world. Further, unsatisfactory experiences of medical consultation that do not address their gaps in knowledge may leave women with an unmet need for information and affect their subsequent engagement with PCOS management and care (9).

Routine consultation needs to go beyond unidirectional, passive guidance on symptom treatment alone. Introducing structured educational elements during consultation in the primary health care setting is therefore important to help acquaint women with their disease and associated comorbidities. One method for patient education, a structured video-based educational module, was tested in the present study to assess its effectiveness in raising awareness about PCOS. The feasibility of introducing such components of patient education as a part of routine consultation is discussed.

Material and Methods

A longitudinal study using one group pretest-posttest design was conducted as a student project, funded by the Indian Council for Medical Research after approval from the All India Institute of Medical Sciences Bhopal Madhya Pradesh India, Institutional Human Ethics Committee and Review Board (approval number: IHEC-LOP/2018/STS0151). Consenting patients with a diagnosis of PCOS were selected to participate using non-probability purposive sampling.

Women aged 18-35 years, diagnosed with PCOS by the Rotterdam criteria (5,6) were included. The Rotterdam criteria, proposed by the group of experts in 2003, require two of three criteria to be met to fit the definition of PCOS: chronic anovulation, clinical and/or biochemical evidence of hyperandrogenism, and polycystic ovaries. Women with menstrual irregularity not fitting the diagnostic criteria, or those with PCOS complicated by chronic medical or surgical conditions were excluded. "Intervention" in the study was structured teaching using a video based educational module. Knowledge was compared before and after exposure to the video. The components of the study are described.

a) Pre-exposure (pre-test) component: Eligible and consenting participants were tested for relevant baseline knowledge using a validated questionnaire delivered via email or other social media platforms.

b) Exposure to educational module (intervention): An educational video (learning module) was shared via email or the preferred social-media platform after completion of the pre-test questionnaire. The module can be assessed at <https://youtu.be/uxw5X6q4494>. The contents of the video are described in Table 1.

c) Post-exposure (post-test) component: The questionnaire was readministered at the end of the video.

The questionnaire for the present study was prepared with a framework to test the knowledge and behavioural attitudes

Table 1. Components of the educational video

Module	Segment 1	Segment 2	Segment 3
Title	Normal menstrual cycle and pathophysiology of PCOS	Importance of lifestyle modification in PCOS	Pharmacological intervention and treatment adherence
Content	A. Video explaining about normal menstrual cycle comprising i. Length of the menstrual cycle, ii. Regularity of cycle, iii. Duration of bleeding & amount of flow. B. An animation explaining pathophysiology of PCOS	Comparative animation regarding healthy and non-healthy lifestyle including a description of role of diet, food supplements, daily physical activity, concept of calorie balance and body mass index, etc.	Animated expert interview regarding indication of pharmacokinetic interventions, their types and importance of treatment adherence. 1. Various treatment options, 2. Annoyances during period, 3. Effect on period after stopping medications, 4. Subfertility & complications during pregnancy, 5. Comorbidities and future health risks associated with PCOS including diabetes, obesity, endometrial cancer etc.
PCOS: Polycystic ovary syndrome			

of participants with PCOS, before and after exposure to the educational module. It consisted of objective-style test content (a combination format of alternate response and close-ended multiple choice questions) consisting of a total of 25 individual questions. Subject matter for questions included, but was not limited to, factual and conceptual knowledge about the normal menstrual cycle, pathophysiology and natural history of PCOS, and behaviour-related awareness about lifestyle modification and treatment adherence in PCOS. An expert

group, consisting of three senior gynaecologists, provided input on clarity, simplicity, and relevance of the content. A pilot test was carried out on a small sample of 20 respondents before being tested on the study population and internal consistency of the questionnaire was tested. The expert group reviewed the tool after pilot testing and provided recommendations on content validity which were incorporated to the revise the questionnaire. The list of questions is described in Table 2.

Table 2. Components of the questionnaire

Q1. Polycystic ovary syndrome or PCOS, a complex metabolic disorder, is diagnosed using Rotterdam criteria. Which of the following is true regarding diagnosis of PCOS with this criterion?	a. Delayed menstruation/irregular menstruation, b. Clinical evidence of excess male hormone (excessive dark coarse hair growth, acne etc), c. Ultrasonography showing enlarged ovaries or multiple small follicles (cysts) in ovaries, d. Any 2 of the above.
Q2. Which organ bleeds during menstruation?	a. Uterus b. Fallopian tube c. Ovary d. All the above
Q3. Which organ produces egg for fertilization with male gamete?	a. Uterus b. Fallopian tube c. Ovary d. All the above
Q4. What is the normal length of one menstrual cycle (in days)?	a. 15-25 b. 21-35 c. 25-40 d. 30-45
Mark symptoms seen in PCOS as true or false	Q5. Delayed menstruation Q6. Acne Q7. Dark, velvety & thickened skin folds Q8. Weight loss Q9. Inability to conceive
Q10. Which organ regulates the hormonal balance for growth and menstruation in female?	a. Pituitary glands b. Pancreas c. Kidney d. Liver
Q11. What is the recommended daily calorie intake to reduce weight in patient with PCOS with an overall sedentary lifestyle?	5000 calorie/day 2100 calorie/day 1200 calorie/day 3300 calorie/day
Q12. Food to be avoided by patients with PCOS	French fries Red meat Processed food Refined sugars All of the above
Q13. How do alternative medicine practices like Yoga and meditation help in women with PCOS?	a. Increasing weight and fertility, b. Reducing weight and stress, c. Reducing weight & stress and increasing fertility, d. None of the above.
Q14. Which of the following symptoms may need medical treatment, if not checked by lifestyle modification ?	a. Delayed menstruation b. Painful menstruation c. Weight loss d. All of the above

Table 2. Continued

Mark following statements as correct/incorrect regarding PCOS	Q15. Obesity is modifiable cause of PCOS, Q16. Lifestyle modifications (Weight control and regular exercise) and pharmacotherapy can prevent complications of PCOS, Q17. Women with PCOD have high risk of diabetes in later life, Q18. Nutritional management has no role in treatment of PCOS, Q19. Polycystic ovary and ovarian cancer are same, Q20. Anovulation is not the cause of infertility in PCOS women.	
Q21. Women with PCOS are at risk of	a. Breast cancer b. Stomach cancer c. Uterine cancer d. Blood cancer	
Match the following drugs in management of PCOS	Q22. Metformin Q23. Anti-androgenic drugs Q24. Hormonal pills Q25. Ovulation induction drugs	a. Insulin Insensitivity b. Infertility c. Acne d. Irregular menstruation
PCOS: Polycystic ovary syndrome		

Scoring

Responses from the participants were scored using a model answer key. A score of “one” or “zero” was awarded for each correct or incorrect answer, respectively, and the sum total for each participant was expressed as the “awareness score” described on an ordinal scale as follows: fair (10 or less), moderate (11-17) and good (18-25).

The maximum achievable score was 25. The difference in awareness scores between the pre-exposure and post-exposure responses was quantified to investigate the effectiveness of the learning modules in increasing knowledge.

The questions were categorised into the following domains based on content. Domain 1 (10 questions) included questions related to the normal menstrual cycle and pathophysiology of PCOS. Domain 2 focussed on the importance of lifestyle management (7 questions) and Domain 3 (8 questions) dealt with the indications for pharmacological intervention and role of treatment adherence in PCOS.

Statistical analysis

Descriptive statistics was used for qualitative data and paired t-test and z-test were used, as appropriate, to compare outcomes. Effect size was estimated to assess magnitude of

effect on knowledge due to intervention (small, medium, or large) (10). Statistical analysis was done manually using MS Excel 2016.

Results

A total of 41 eligible participants completed both pre- and post-test questionnaires. Most women (92.6%) belonged to middle or lower socio-economic classes and all had completed a minimum of higher secondary education. Age distribution of the participants was 20% aged 18-21 years, 39% aged 22-26 years, and 41% aged 27-35 years. Only 29.2% of the women primarily attended clinic for infertility while the rest sought consultation for menstrual irregularities.

Mean ± standard deviation awareness score prior to intervention was 15.09±4.31, which increased to 18.60±3.85 after the intervention. This increase indicated a better understanding of the disease condition when tested using the paired t-test (t=9.6722; p=0.00001). Younger participants, aged ≤26 years scored better with higher pre- and post-test scores (Table 3). Most (48.8%) of the respondents had baseline awareness in the “moderate” range (scores between; 11-17) whereas post intervention scores improved to the “good” category for 63.4% of the women (Table 4, 5).

Table 3. Awareness scores

	Age (years)	n	Pretest score (mean ± SD)	Post test score (mean ± SD)	Paired t-test
All respondents	18-35	41	15.09±4.31	18.60±3.85	t=9.6722; p=0.00001
Age subset	18-21	16	16.44±2.96	19.50±3.05	t=9.1411; p=0.00001
	22-26	18	16±3.92	18.83±4.25	t=14.0185; p=0.00001
	27-35	7	9.71±4.19	16±3.78	t=3.8590; p=0.0083
SD: Standard deviation					

Table 4. Awareness score

	Number of women in each category based on awareness score (n)	
	Pre-test	Post-test
Fair (10 or less)	7 (17.07%)	3 (7.32%)
Moderate (11-17)	20 (48.79%)	12 (29.27%)
Good (18-25)	14 (34.14%)	26 (63.41%)

Table 5. Question domain-wise responses in pretest and post-test

Question groups	% Respondents who answered correctly (pre-test)	% Respondents who answered correctly (post-test)	Z-test
Domain 1	75	91	p<0.00001
Domain 2	57	86	p<0.00001
Domain 3	52	70	p<0.00001

Furthermore, effect size was calculated for the pre- and post-intervention data sets using Cohen's d value. Cohen's d was 0.85, meaning intervention with teaching modules had a significantly large effect on knowledge, suggesting effectiveness of the teaching method.

Feedback received from the participants was positive. The majority (90.2%) were satisfied with the consultation experience and 92.7% agreed that the video helped them gain new perspectives towards their disease.

Discussion

The study was done to assess the educational value of a structured teaching method in raising awareness of PCOS in an outpatient setting. The educational module was effective in increasing awareness and changing subjective perspective about PCOS as demonstrated by a significant increase in the overall awareness score. In addition, the intervention was shown to have a significant impact of patients' understanding of their condition, as demonstrated by the Cohen's d value. Results of the present study are consistent with previous studies where a similar structured teaching program has shown been shown to have a significant impact on disease knowledge in participants from varied educational backgrounds (11-14).

Participation in the present study required a minimum level of literacy, economic stability (possession of a smart phone or computer) and familiarity with the internet. These socio-economic factors may be reflected in the relatively higher levels of baseline awareness demonstrated by the participants with an average pre-test score of 15.09. Higher pretest scores noted in the two younger age groups suggest changing age-related

societal level processes, in part due to an increase in the use of the internet for information and communication amongst young people. However, the quality of information available from the internet and other commercial entities is known to be inconsistent and lacking credibility (15,16).

Empowering women by increasing health literacy becomes even more crucial for those from disadvantaged backgrounds with little or no access to reliable information. Structured teaching remains relevant in such populations, which includes adolescent girls from rural India. A meaningful gain in knowledge has been reported using teaching modules customized to accommodate local culture and perceptions (13,14).

PCOS is a chronic multisystem disorder with considerable variation in symptom expression. Lifestyle change and nutritional management remain the first line of management for all, even in women with a lean PCOS phenotype, as there is a strong association between abdominal obesity and insulin resistance in women with PCOS who are not markedly overweight (17). Lifestyle change is multifactorial and includes goal setting, self-monitoring, stimulus control, slower eating, reinforcing changes, and prevention of relapse to optimise physical and emotional health in women (18). Even modest reform of an individual's approach to nutrition and exercise drastically improves endocrine features, reproductive function and cardiometabolic risk profile, even without marked weight loss (19). A key shift in cognitive behaviour should be the goal, as short-term diets, exercise and therapies rarely lead to a permanent effect. The message should be emphasized at every clinic visit and customized teaching tools should be used routinely to reinforce it.

The present study demonstrated the positive impact of a suitable and well-timed intervention, in this case patient education occurred at the time of consultation, in increasing patient awareness, which can translate into long term behaviour change. Though direct and indirect evidence about this is available, focus on disease literacy during consultation is not routine and practical information related to lifestyle for symptom management and preventing long-term complications of PCOS, is not often provided (8,15,16,20,21). Introduction of a brief but focussed educational element in outpatient settings involves almost no cost after development and little inconvenience. Where appropriate, the managing clinician should take on the primary responsibility for educating patients, to ensure continued understanding of the disorder, life course implications, engagement in lifestyle improvement, and participation in regular screening for metabolic complications (21). Consultation visits may be the best time to educate and reinforce behavioural change, as patients are more receptive to the inputs with respect to

functional understanding of the diagnosis, role of continued care and long term implications. This study provided evidence of a significant change in awareness and perception of PCOS that was achieved from a small intervention with minimal effort. This may be important in improving long term health outcomes in PCOS.

Study limitation

The main limitation of the study was the small and homogenous sample, as recruitment was from a single centre. However, the large effect size, even in such a small homogeneous group, suggested the possible utility of this approach in a more heterogeneous group of participants. To test this hypothesis there would be a need for a set of validated teaching modules adapted to local language, customs, and cultural perceptions, that would be accessible by a wider population. A subsequent comparative analysis on heterogeneous groups of participants would be needed. Inclusion of a control group with crossover design would further increase internal validity.

Conclusion

Patient education using simple teaching tools during routine consultation provided an opportunity to improve patients' knowledge of PCOS and the life course implications for PCOS. Empowering patients by improving disease literacy will promote preventive aspect of health care. This is important in the management of this chronic disorder, PCOS.

Ethics Committee Approval: A longitudinal study using one group pretest-posttest design was conducted as a student project, funded by the Indian Council for Medical Research after approval from the All India Institute of Medical Sciences Bhopal Madhya Pradesh India, Institutional Human Ethics Committee and Review Board (approval number: IHEC-LOP/2018/STS0151).

Informed Consent: Informed written consent was obtained from all participants.

Peer-review: Externally peer-reviewed.

Author Contributions: Concept: A.G., Ar.G., A.H.; Design: A.G., A.H.; Data Collection or Processing: A.G., P.D., Ar.G., A.H.; Analysis or Interpretation: A.G., P.D., A.H.; Literature Search: A.G., P.D., A.H.; Writing: A.G., P.D., Ar.G., A.H.

Conflict of Interest: No conflict of interest is declared by the authors.

Financial Disclosure: The authors declared that this study received no financial support.

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