REVIEW

Education and Self-Management for Women with Polycystic Ovary Syndrome; a Narrative Review of Literature

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Abstract

Polycystic ovary syndrome (PCOS) is the most common endocrine condition in women of reproductive age and is associated with high risk of long term metabolic and psychological conditions such as diabetes, cardiovascular disease and depression. These patients present at a young age to the health care system and seek information about their condition. A structured education program seems to be able to answer these questions. Structured education self-management programs are pragmatic and cost-effective patient-centered group educations which are underpinned by learning theories and empower patients to take control of their management and reduce their associated long term risks. In this paper, we introduce structured education programs and review the evidence of education programs for women with PCOS.

Key Words: Self-management, Structured education, Polycystic ovary syndrome.

Background

Polycystic ovary syndrome (PCOS) is one of the most common endocrine abnormalities in women with a reported prevalence of up to 18% depending on the diagnostic criteria used (1-3). Over years the diagnosis and description of PCOS have changed. The first descriptions of PCOS were made around 2,500 years ago by Hippocrates in his notes on the "diseases of women" where he described "young women who do not become fertile despite having menstruation" and also attributed "general ill health" to the women who did not have any menstruation at all (4). "Ibn-Sina" (980 – 1037 A.D.) described a group of women with amenorrhea who have "masculine features and are generally obese" (5). In the nineteenth century, Rokitanski gave a detailed description of the anatomical and morphological changes which happened in an ovary affected by multiple cysts and described it as an "anomaly of texture"(6). It was not until Stein and Leventhal combined their findings of abnormal ovarian morphology with hirsutism and amenorrhea to describe the syndrome in 1935 (7). PCOS is now diagnosed based on the presence of two out of three major criteria (8,9); A) Clinical or biochemical hyperandrogenism; B) Anovulation (chronic or oligo) which is defined as having less than 10 menstruation in a year (> 35 days intervals between menstruations) or evidence of the lack of ovulation despite regular menstruation. C) Polycystic ovaries on ultrasound. Table 1 summarizes the 4 possible phenotypes of PCOS based on the latest Rotterdam criteria (8).

Women with PCOS are often young (8,10) and emotionally distressed by their condition (11). The diagnosis of PCOS has a major impact on a woman's life; they have higher risk of impaired glucose regulation or pre-diabetes, type 2 diabetes mellitus (T2DM), obesity, metabolic syndrome, fatty liver disease, hypertension, dyslipidemia, cardiovascular diseases, sleep apnea, gestational problems, as well as depression (8-20). It is therefore a chronic condition with long lasting effects on women's life and therefore to reduce their long term cardiovascular and diabetes risk and improve their quality of life, a patient education and empowerment should also be a priority for these patients as it is for other chronic conditions such as diabes (21,22). An essential part of this empowerment is increasing patient understanding of their condition through education program (23,24) and there is a growing body of evidence showing the effectiveness of such program in lifestyle change and improving the cardiovascular risk (25-27)

In this article we introduce structured education program and review the evidence of education program for women with PCOS.

Methods

This is a narrative review, after conducting a search on PubMed and EMBASE for articles related to "patient education" AND "Polycystic Ovary syndrome" up to Oct 2013. A Rich Site Summary (RSS Filter) was subsequently set up on PubMed for any article related to PCOS.

What are structured self-management interventions?

Self-management interventions are complex interventions that are designed to empower individuals who suffer from long-term conditions. Their aim is to motivate and increase confidence in those individuals with or at risk of a long-term condition to allow them to effectively carry out the daily decisions required to manage their condition and/or to make necessary lifestyle changes (28). In the UK, successful self-management interventions are well established in diabetes care with robustly evaluated national program such as Dose Adjustment for Normal Eating (DAFNE) [http://www.dafne.uk.com/] for patients with type 1 diabetes and Diabetes Education and Self-Management for Ongoing and Newly Diagnosed (DESMOND) [http://www.desmond-project.org.uk/] for those with type 2 diabetes. These programs fulfil the standard criteria set out by the Patient Education Working Group (24); as being evidence-based, with a structured written curriculum, trained educators, quality assured, and audited. Figure 1 shows the principle elements of DESMOND education program. Although these criteria are set out for diabetes education programs, they can be applied to any long-term condition.

The literature shows that patients with chronic conditions express a need for education and generally feel better when they understand their condition (29,30). It is well known

Table 1. Four Possible phenotypes of PCOS

Features	A	B	D	E
Hyperandrogenism	+	+	+	-
Oligo-anovulation	+	+	-	+
Polycystic Ovaries	+	-	+	+
Rotterdam Criteria (8)	√	√	√	√
√ Diagnosed with the criteria.				

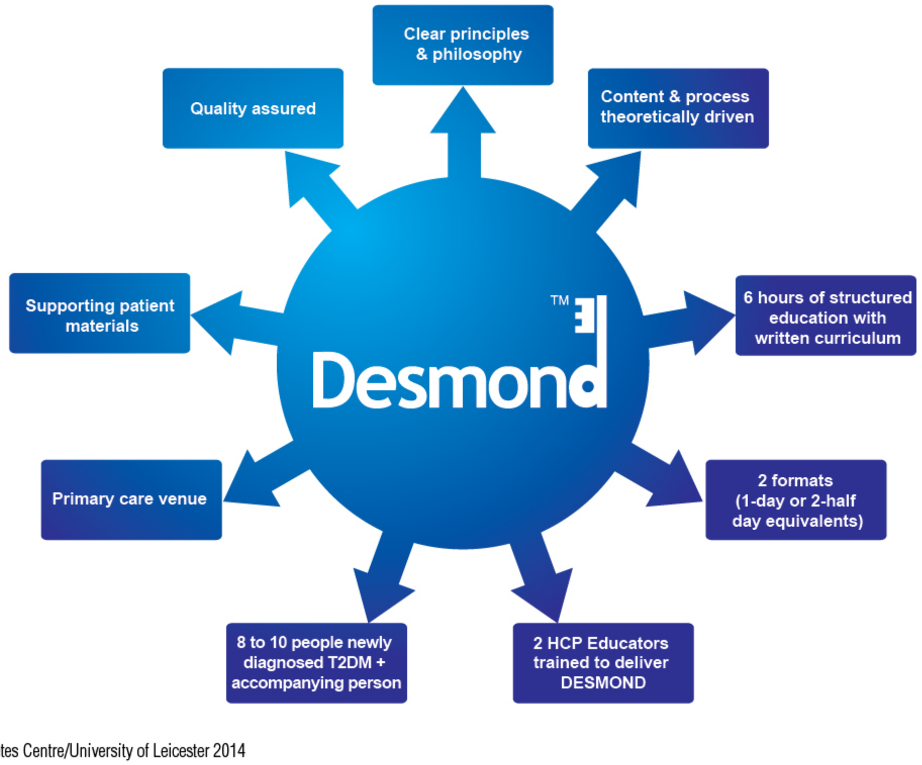

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Figure 1. An illustration of the "diabetes education and self-management for ongoing and newly diagnosed (DESMOND)" program: an intervention model developed in Leicester Diabetes Centre programs (ref 62). Reproduced with permission.

that any patients with a chronic condition seeks information about their condition to understand the five dimensions of the illness: timeline, consequences, cure/control, identity, and cause (31,32). Structured education programs explore these 5 dimensions and use different learning theories in patient-educator interaction to eventually increase patients understanding of their condition and offer self-management strategies for cure/control and lifestyle change (33). Figure 2 shows an example of a model used in DESMOND education programs.

What do women with PCOS want and what is available for them?

Women with PCOS feel that they are "not being taken seriously" (34), they feel there is lack of communication with health care systems (34,35) and their emotional and psychosocial needs are not met (35,36). Some of the major themes encompassing women's lived experience of managing PCOS are "frustration", "confusion", "searching", and wanting to "gain control"(35,37,38). Lack of information has been shown to be associated with the poor health related quality of life (HRQoL) in this group (30). One study showed that women with PCOS are more anxious than the age-matched non-PCOS women about their infertility, obesity, and long term health risks such as diabetes even at a young age group of 18-25 (39). This is also true for the teenagers who are keen to know more about the nature of the condition and emotional and physical aspects of PCOS (34). Providing information improves the quality of life in women with PCOS (40) and education about their condition improves their understanding of causes and treatment choices (41).

They would like to get information about the condition from their doctor (38,42) although this does not happen in majority of the patients (34,35,42), and leaves them with "frustration" (35). Patients eventually refer to the internet as their main source of information (42). The variety of on-line forums/chat rooms and websites is possibly an indication of these patients' need to explore and find information. Websites like; "NHS choice", "SoulCysters", "Daily Strength", "Verity website/ (facebook page)" and many more are full of questions asked by patients and trends of conversations about different PCOS related

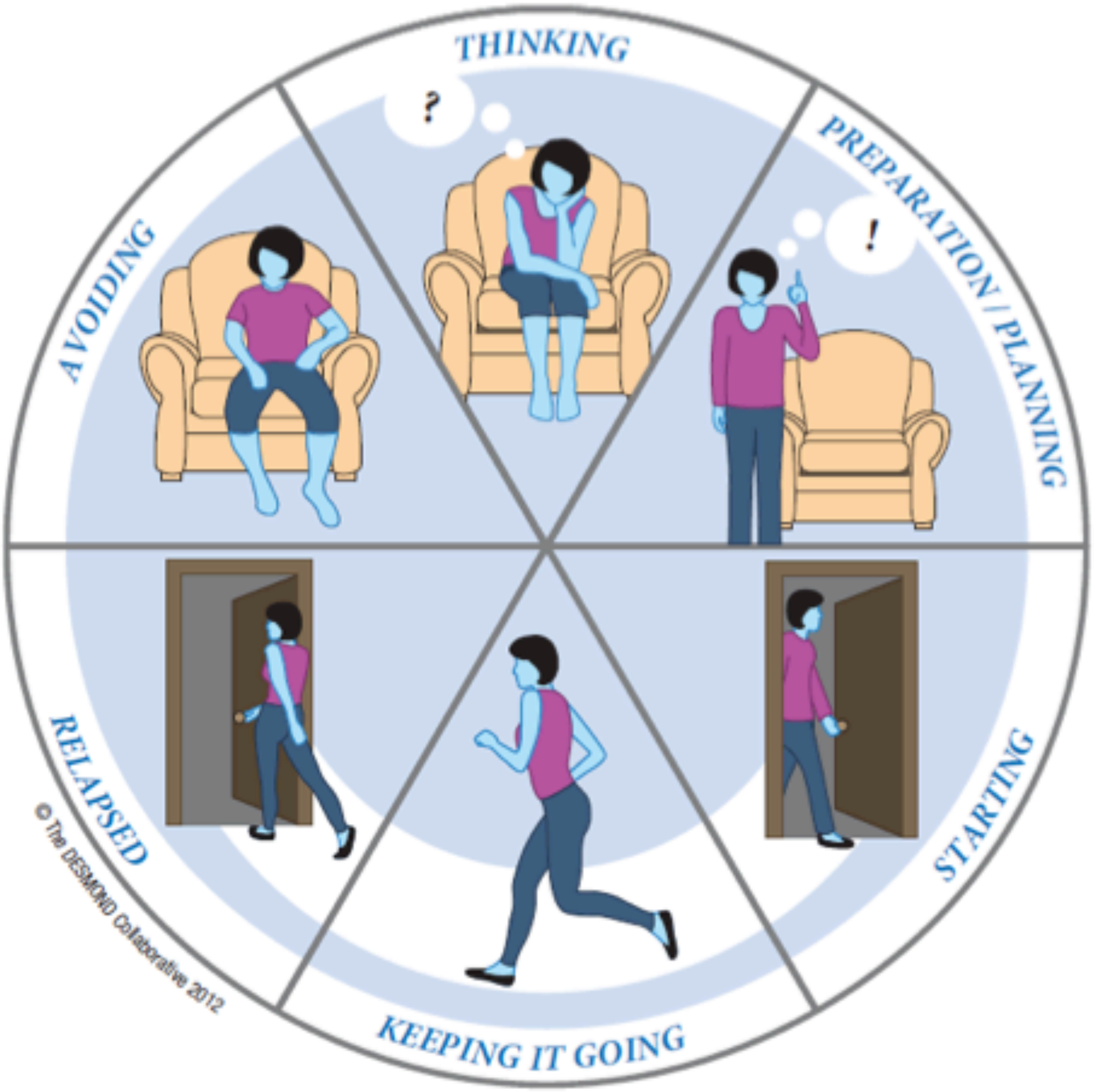

Figure 2. The “cycle of change” used in DESMOND education programs (from ref 66).

signs, symptoms, treatments and complications. However, the information on the internet is not necessarily clear and concise, and users may need to refer to multiple sites to find their answers (43). Another problem with the internet is the lack of direct interaction with others and the level of peer support. Women with PCOS seek to have the support and look positively at peer support groups (44).

Increasing knowledge, understanding the underlying condition and interaction with peers are the main elements of a group based structured education program. There is, however, a lack of evidence for “structured education program” for women with PCOS. In a clinical research study aimed at investigating the ultrasound morphology of ovaries the participants (n=68) received education about PCOS from the researcher (gynecologist) during the research visit (41). In the post-study internet survey these women indicated that direct education about physiology, underlying pathology and treatment choices and their mechanisms of actions in PCOS had been very helpful. Almost a third of these patients did not know that PCOS could present with a variety of signs and symptoms and found the advice from a health care professional (the doctor) helpful regarding the lifestyle changes (41). In research studies, information has been usually provided during a lifestyle intervention about the specific lifestyle change such as dietary (45-48) or physical activity (49) or both (50-53). Although there are some beneficial effects of lifestyle interventions on weight, waist circumference and insulin indices as evidenced by systematic reviews (54,55), but they hardly talk about patient education. There are few mentions of group interactions (51) or individual psychological input (56), and only in one study (57) the dietician reviews PCOS for participants as a disease and the benefits of diet on their risk factors (with no details provided) in an individual visit with participants. Clearly there is a gap in evidence and service provision of structured education for women with PCOS.

What can be offered?

Women with PCOS suffer from a chronic condition, which puts them at high risk of diabetes and cardiovascular disease. In an extremely conservative estimation towards a lower estimation the reported overall cost of PCOS in the USA was around $4.37 billion in 2004(58). The breakdown of the cost of PCOS was 2.1% for initial evaluation, 40.5% for PCOS-associated diabetes and the rest for treating menstrual dysfunction/abnormal uterine bleeding, infertility, and hirsutism.(58) Given that up to 69% of patients with PCOS never seek any medical advice for their symptoms (1,10) and therefore have no recorded history in the health care system, and the fact that mental health problems related to PCOS have not been incorporated into this cost analysis, the socio-economic impact of PCOS is likely to be significantly higher than the figures presented in the above study.

It therefore seems logical to think of interventions which can reduce long term health risks associated with the condition and improve patients' quality of life. Prevention of diabetes and cardiovascular diseases are highly recommended in the health system (26,27) and evidence shows that introduction of lifestyle interventions in the population at risk of diabetes is the most cost-effective approach in prevention of diabetes (26,59,60). Patient centered education programs, which have been successful in increasing walking steps (61) or weight reduction (62) and illness perception even three years after a single 6 hours education program (63) have proved to be extremely cost effective (64) and therefore, pragmatic to implement in the health system (65). A similar model can be used to develop tailored structured education program for women with PCOS. Currently there are some studies on-going which are exploring this approach such as "structured education program to reduce Cardiovascular risk in women with Polycystic ovary syndrome (SUCCESS study) which is a randomized controlled trial aiming at testing such program NCT01462864.

Conclusion

Polycystic ovary syndrome is a common chronic condition and is associated with high risk of long term metabolic and mental health conditions such as diabetes, cardiovascular disease and depression. Women with PCOS present at a young age to health system and seek information about their condition. Structured education programs may be able to answer these questions and empower patients to take control of the associated long term risks but more research in this field is required.

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Conflict of Interest

None related to the presented work. KK and MJD are advisors to the Department of Health NHS Health Checks program and are members (KK Chair) of the NICE Program Development Group (PDG) on 'Preventing T2DM: risk identifications and interventions for individuals at high risk'

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