

Original Paper

Developing a Novel Web-Based Self-Management Support Intervention for Polycystic Ovary Syndrome: Mixed Methods Study With Patients and Health Care Professionals

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Abstract

Background: Polycystic ovary syndrome (PCOS) represents a significant global health burden requiring urgent attention. This common chronic endocrine and cardiometabolic condition affects around 1 in 10 women and individuals assigned female at birth, with significant adverse effects on well-being, quality of life, and mental health, as well as serious and complex long-term health consequences. International guidelines for best health care practice recommend the provision of comprehensive cognitive behavioral interventions to support self-management and improve health outcomes for those living with PCOS. Web-based health interventions have the potential to meet this need in an accessible and scalable way.

Objective: We aim to identify barriers to self-management and psychological well-being in women with PCOS and adapt a web-based self-management program to provide a prototype digital support intervention for them.

Methods: We adapted an existing support program (HOPE) for PCOS using the antecedent target measure approach. We conducted qualitative interviews with 13 adult women living with PCOS, 3 trustees of a patients with PCOS advocacy charity, and 4 endocrinologists to identify “antecedents” (barriers) to self-management and psychological well-being. Framework analysis was used to identify potentially modifiable antecedents to be targeted by the novel intervention. At a national conference, 58 key stakeholders (patients and health professionals) voted for the antecedents they felt were most important to address. We used research evidence and relevant theory to design a prototype for the PCOS intervention.

Results: Voting identified 32 potentially modifiable antecedents, relating to knowledge, understanding, emotions, motivation, and behaviors, as priorities to be targeted in the new intervention. A modular, web-based prototype HOPE PCOS intervention was developed to address these, covering six broad topic areas (instilling HOPE for PCOS; managing the stress of PCOS; feeding your mind and body well; body image, intimacy, and close relationships; staying healthy with PCOS; and keeping PCOS in its place).

Conclusions: We identified barriers to self-management and psychological well-being in women with PCOS and used these to adapt a web-based self-management program, tailoring it for PCOS, which is a comprehensive group intervention combining education, empowerment, lifestyle management, peer support with cognitive behavioral tools, and goal-setting (to be delivered by peers or codelivered with health care professionals). The modular structure offers flexibility to adapt the program further as new clinical recommendations emerge. The intervention has the potential to be delivered, evaluated for feasibility, and, if effective, integrated into health care services. Self-management interventions are not designed to replace clinical care; rather, they serve as an additional source of support. The HOPE PCOS program conveys this message in its content and activities. Future research should evaluate the prototype intervention using primary outcomes such as measures of psychological well-being, self-management self-efficacy, depression, anxiety, and PCOS-related quality of life. They should also assess the intervention’s acceptability, scalability, and cost-effectiveness.

KEYWORDS

anxiety; depression; PCOS; peer support; polycystic ovary syndrome; positive well-being; psychoeducation; self-management; web-based health intervention; women's health

Introduction

A Complex Condition With Serious Physical and Mental Health Consequences

Polycystic ovary syndrome (PCOS) represents a significant global health burden requiring urgent attention [1]. It is a common chronic cardiometabolic condition affecting around 1 in 10 women and individuals assigned female at birth. PCOS has diverse symptoms, for example, acne, alopecia, hirsutism, obesity, impaired glucose metabolism, menstrual disturbances, and subfertility [2-4]. It has significant adverse effects on well-being, quality of life, and mental health. For example, compared with healthy controls, women with PCOS have lower health-related quality of life and higher scores on symptoms of depression and anxiety [5-9], and appear to be at risk for disordered eating [10-14] and unhealthy weight management practices [15]. There is also evidence that women with PCOS may experience impaired sexual satisfaction [16], which may impact relationship satisfaction for those in intimate relationships [17]. The adverse mental health impact of PCOS may have been worsened during the COVID-19 pandemic, as patients faced an uncertain risk of contracting COVID-19, more limited access to health care services, and barriers to using their normal support strategies [18].

PCOS has serious and complex long-term health consequences [19,20]. Women with PCOS are at increased risk of sleep disturbances [21] and obstructive sleep apnea [22,23] and appear to have an elevated risk for postpartum depression [24]. They also have an increased risk of developing type 2 diabetes and cardiovascular complications [4]. Hospital admission rates for patients with PCOS have been reported to be twice as high as those without the condition [25].

The Need for Self-Management Support

PCOS is a long-term condition with no cure, having a wide range of treatment options but no single treatment that targets every symptom or concern. Treatments are often complex and multifaceted and often include recommendations for lifestyle change, for example, altering diet and increasing physical activity [4]. Considerable self-management is required on the part of those living with PCOS, including adherence to treatment. There are wide disparities in adherence, with 1 review suggesting adherence rates ranging from 21.7% to 86% [26]. A large-scale survey suggests women with PCOS are open to adjusting their diet and physical activity to improve their health, but few achieve their goals [27].

Recent qualitative research [28-33] has identified that women with PCOS face a range of barriers to following health professionals' lifestyle advice, including limited access to credible information, time, cost, and lack of access to safe exercise spaces, with some women lacking adequate social support, having unsupportive partners, or struggling to prioritize

their own health because of responsibilities for feeding children [29]. In addition, women's motivation and capability to adhere to recommended lifestyle changes may be impacted by the complex and multifaceted nature of PCOS, including fatigue, anxiety, depression, difficult emotions, disordered eating, the impact of stress, sleep disturbances, and a lack of critical health literacy [28,29,31-33]. Features of PCOS itself may add to the burden of following lifestyle advice, especially around weight management. For example, altered regulation of gut hormones and energy expenditure may affect women's capability to follow diet and exercise regimes [28].

The Need for Comprehensive, Evidence-Based, Coproduced Interventions

Patients with PCOS value specialized, integrated health care services [34], and it has been argued that the ideal model of care would be "evidence-based, patient-centered, codeveloped by consumers and health professionals" [35]. International guidelines advise (in addition to appropriate medical treatment) "Comprehensive health behavioral or cognitive behavioral interventions could be considered to increase support, engagement, retention, adherence, and maintenance of a healthy lifestyle and improve health outcomes in women with PCOS." [4]. There is therefore scope for developing new interventions that combine education and cognitive behavioral approaches with peer support to promote physical activity, healthy eating, and emotional well-being in women with PCOS. This multifaceted approach reflects the tradition of long-term self-management that is well established in other endocrine conditions, such as diabetes [36]. Self-management is arguably broader than lifestyle change, referring to what patients must do to manage their own health in collaboration with health professionals [37,38]. This may include behavior change but also requires emotional regulation, coping, and maintaining general well-being, such as self-worth, a positive outlook, and hope [39].

Objectives for This Study

The first aim of the study was to identify barriers to self-management and psychological well-being in women with PCOS. The second aim was to combine insights from these data to cocreatively adapt an existing web-based program to offer a prototype peer-delivered, self-management intervention to empower and support women with PCOS to enhance their psychological well-being and, if they chose to, to make appropriate lifestyle changes to self-manage their condition.

To develop our novel self-management intervention for PCOS, we selected an existing intervention that has been researched and evaluated with multiple patient groups. The HOPE program [40] is a complex intervention for long-term condition self-management with a distinctive theory and evidence base from positive psychology [41]. The HOPE program has reduced anxiety and depression and increased positive well-being for

people with a range of health conditions and support needs, for example, people living with multiple sclerosis [42], parents of children with developmental disorders [43], and people living with and after cancer [44].

Methods

Approach to Intervention Development

The UK Medical Research Council's (MRC) guidance on developing complex interventions [45,46] recommends that intervention development should be "a dynamic iterative process, involving stakeholders, reviewing published research evidence, drawing on existing theories, articulating program theory, undertaking primary data collection, understanding context, paying attention to future implementation in the real world, and designing and refining an intervention using iterative cycles of development with stakeholder input throughout" [46]. The most recent framework commissioned by the National Institute of Health Research and the MRC [47] further emphasizes the importance of developing interventions that are "implementable, cost-effective, transferable, and scalable in real-world conditions." This may include adapting existing interventions and using existing, for example, digital infrastructure, rather than developing wholly new interventions ab initio. We chose to adapt and tailor an existing intervention to build on its previous successes and use its proven, scalable digital infrastructure to offer a PCOS intervention that would be as implementable, transferable, and scalable as possible.

The HOPE cancer program from which this intervention was adapted [44] was developed following the MRC recommended processes and continues to undergo refinements as each cohort or variant of the program is completed. In adapting HOPE for PCOS, we conducted an initial needs assessment with key stakeholders, reviewed published research evidence from primary sources, review papers, and international clinical guidelines, and drew on established and emerging theories about psychological well-being to produce a prototype digital intervention [48] that could be subjected to feasibility testing.

Underpinning Theory and Evidence: Self-Management Versus Behavior Change

Interventions in the field of health behavior are more likely to be successful if they are theory-based [49]. A number of different approaches were considered for adapting the existing HOPE program, including the behavior change wheel [50] and intervention mapping [51]. However, both of these approaches require very clear specification at the outset of the intervention design of what the target behavior is that the intervention seeks to increase, decrease, promote, or modify. "Lifestyle change" is recommended as a first-line treatment in relation to the management of PCOS, and this often refers to changes to diet and physical activity. However, there is as yet no international consensus as to what precise optimal self-management behaviors might be in PCOS, and it was felt that the groundwork was lacking for the development of a behavior change intervention per se. Given the diversity of the PCOS population, for example some are lean, some are living with overweight and obesity, some are trying to conceive, others are not, some are physically

active, some are more sedentary, some have issues around eating, and others are not, the development of a behavior change intervention to meet the needs of all these was beyond the scope of this study. As our objective was to adapt the existing HOPE program to support self-management, reduce depression and anxiety, and promote psychological well-being rather than develop a completely new intervention from scratch, we used the design process outlined in the following sections.

Cocreation Process

An iterative process of cocreation was used to develop the intervention, using a mixed methodology. An initial needs assessment was conducted with key stakeholders, following the antecedent target measure (ATM) approach [52,53]. This is a flexible model that has been used in the development of previous self-management interventions, for example, for people living with cancer or dementia [54,55].

Initial Data Collection

Semistructured interviews were conducted with women living with PCOS, trustees of the Verity UK PCOS charity who themselves had PCOS, and endocrinologists who provided services to patients with PCOS at a large publicly funded teaching hospital.

Participant Characteristics

Those with lived experience of PCOS were 13 adult women recruited through purposive sampling from social media. All had received a formal diagnosis of PCOS from health professionals at least 6 months before the study and took part in individual interviews. The Verity trustees were 3 adult women, all diagnosed with PCOS by National Health Service (NHS) clinicians, who volunteered to be interviewed to assist with the "cocreation" of the new intervention. The health professionals interviewed in December 2016 were 4 endocrinologists working for a large UK NHS teaching hospital, which has a specialist clinic for PCOS.

Procedure

Interviewees were presented with the problem statement "Some women with PCOS struggle to cope and self-manage effectively" and asked if they agreed and, if so, to give all the reasons why. The reasons given ("antecedents" in the terminology of ATM) were typically difficulties women experience with PCOS and in self-managing their condition. Interviews continued until participants felt they had exhausted all the antecedents they viewed as relevant for PCOS. Antecedents and the conversation through which they were generated were audio recorded and transcribed verbatim for the patient interviews. Antecedents were transcribed contemporaneously for the trustee and health professional interviews.

Analysis

All the antecedents generated across interviews were collated and analyzed thematically following the framework analysis approach to theme development [56] to identify potential targets for intervention. When targets were chosen for intervention, only those considered to be potentially amenable to change by a self-management intervention were selected. For example,

the following antecedents were excluded: endocrine characteristics of PCOS itself, social and environmental factors such as stigmatizing behavior from others, and issues with the health care system such as general practitioners' awareness of PCOS. Once antecedents judged to be unsuitable targets for the intervention were excluded, 36 potentially modifiable antecedents remained.

Stakeholder Voting on Priorities for Intervention

A web-based survey was created listing the 36 modifiable antecedents, and delegates at a national public engagement conference were asked to rate each of these on a 5-point scale of how important they would be to target in a self-management intervention (0=not at all important, 1=somewhat important, 2=important, 3=extremely important, and 4=crucial). Conference delegates included patients with PCOS and advocates and some health professionals treating PCOS, of whom 58 voted in the survey. All modifiable antecedents scoring 2.5 or above were retained as intervention targets; antecedents scoring below 2.5 were discarded.

Literature Searches for Intervention Targets

Literature searches were conducted, and clinical guidelines were consulted to generate further intervention targets. Review and systematic review papers [2,16,57-68] were reviewed alongside an international clinical guideline for the management of PCOS [4]. No new targets were generated from the literature, which confirmed the findings from the needs assessment with key stakeholders.

Adaptation of Existing Digital Intervention and Consultation With Stakeholders

The existing HOPE program has previously been specified using the Practical Reviews in Self-Management Support (PRISMS) self-management intervention taxonomy [69], and new

intervention components were mapped onto or added to the program specification. New program content specific to the prototype PCOS program was created to complement the existing HOPE program materials. A paper prototype was presented to key stakeholders from the PCOS support charity, and following discussion, the new program materials were created and uploaded into the secure web-based platform that hosts the HOPE program. This produced a 6-week web-based intervention ready for feasibility testing.

Ethical Considerations

This study received clearance from the Coventry University Research and Ethics Governance Committee (approvals P40730, P44631, and P45355). For the data collection from health care professionals, NHS Research Ethics Committee approval was not required. A letter of access for research was provided by the Research, Development, and Innovation office of the University Hospitals Coventry and Warwickshire NHS Trust. Participants provided written, informed consent before being interviewed. Patients with PCOS and health care professionals at the public engagement event completed a digital informed consent statement before completing the web-based voting survey. Interview transcripts were anonymized for analysis. No personally identifiable data were collected in the voting survey. No compensation was offered to any participants.

Results

Stakeholder Needs Assessment and Voting

Table 1 shows the list of modifiable antecedents presented in the next stage of the intervention design.

Figure 1 shows a diagrammatic representation of the logic model developed from the PCOS self-management needs assessment done with stakeholders.

Table 1. Modifiable antecedents of polycystic ovary syndrome (PCOS) self-management and psychological well-being in order of priority, as voted on by patient and health care professional delegates at the public engagement event.

Potentially modifiable antecedent	Mean score
Knowledge and understanding: long-term implications of PCOS	3.34
Knowledge and understanding: how to get the most from the health care system	3.31
Knowledge and understanding: how to eat well in PCOS	3.26
Emotions: low self esteem	3.21
Knowledge and understanding: what self-management of PCOS entails	3.19
Knowledge and understanding: how to use physical activity to manage PCOS	3.12
Knowledge and understanding: which information sources to trust	3.12
Motivation: women may find it hard to maintain motivation long-term	3.12
Emotions: feeling not properly feminine	3.09
Knowledge and understanding: the basic biology of PCOS	3.09
Emotions: depression and low mood	3.07
Behaviors: women may not follow a PCOS-healthy diet	3.02
Emotions: struggling to make healthy choices	3.02
Behaviors: women may eat in disordered ways, for example, binge eating and overeating	3.00
Motivation: women may lack motivation to self-manage	3.00
Emotions: embarrassment and shame	2.95
Motivation: women may have low confidence to self-manage	2.95
Behaviors: women may not use physical activity to manage their PCOS effectively	2.91
Emotions: lack of trust in health professionals	2.91
Emotions: anxiety and fear	2.90
Behaviors: women may not prioritize their own needs effectively	2.88
Motivation: women may lack clear self-management goals	2.79
Behaviors: women may avoid or give up on self-management	2.76
Emotions: frustration and anger	2.71
Emotions: loneliness and isolation	2.71
Motivation: women may not find physical activity enjoyable	2.67
Skills: women need better skills to communicate needs to health professionals	2.62
Behaviors: women may not self-monitor their menstrual cycle effectively	2.60
Motivation: women may be in denial and avoid trying to self-manage	2.60
Motivation: women may have unrealistic goals	2.59
Knowledge and understanding: women may have unrealistic expectations of the female body	2.57
Behaviors: women may isolate themselves from social contact	2.52
Behaviors: women may hide their self-management activity from others ^a	2.47
Motivation: women may not be ready yet to start self-managing ^a	2.41
Behaviors: women may not take medications as prescribed ^a	2.21
Behaviors: women may self-harm ^a	2.17

^aPotential antecedents scoring below 2.5 were discarded as intervention priorities. This left 32 antecedents that were targeted by the new intervention, 10 of which were thematically categorized in the framework analysis under behaviors, 9 under emotions, 8 under knowledge and understanding, 8 under motivation, and 1 under skills.

Figure 1. Logic model of modifiable antecedents to polycystic ovary syndrome (PCOS) self-management and psychological well-being identified in a mixed methods study of patients and health care professionals.



In a typical ATM design, logic models are often presented as linear processes in which 1 antecedent, such as knowledge or understanding, is represented as preceding another, such as motivation or behavior. We have selected the metaphor of interlocking gears for our schematic logic model on the assumption that knowledge, understanding, skills, motivation, emotions, and behavior interlock and may drive or impede each other, at times facilitating or hampering effective self-management. For example, a person might gain helpful knowledge about their condition, but without developing skills to apply this to practice, they might be unable to engage in effective self-management behaviors. Similarly, a person might

have adequate knowledge, understanding, and skills to manage their condition, but difficult emotions might adversely impact their motivation and prevent effective self-management. This logic model was used to inform the adaptation of the existing HOPE program framework to produce a specific version for PCOS.

Mapping Modifiable Antecedents Onto Intervention Content

Table 2 shows how the antecedent “problems” derived from the logic model were mapped onto solution-focused content across 6 sessions of the prototype intervention.

Table 2. Mapping of antecedents of polycystic ovary syndrome (PCOS) self-management and psychological well-being onto new PCOS self-management intervention session content.

Potentially modifiable antecedent	Course sessions					
	1	2	3	4	5	6
Long-term implications of PCOS	✓		✓		✓	
Getting the most from the health care system	✓			✓	✓	✓
How to eat well in PCOS		✓	✓			
Coping with low self esteem	✓	✓	✓	✓	✓	
What self-management of PCOS entails	✓	✓	✓	✓	✓	
How to use physical activity to manage PCOS	✓	✓	✓			
Which information sources to trust	✓	✓	✓	✓	✓	✓
Maintaining motivation longer term	✓	✓	✓	✓	✓	✓
Coping with feeling “not properly feminine”	✓		✓	✓		✓
Basic biology of PCOS	✓		✓	✓	✓	✓
Coping with depression and low mood	✓	✓	✓	✓	✓	✓
Following a PCOS-healthy diet	✓		✓			
Making healthy choices	✓		✓			
Coping with eating distress, for example, binge eating and overeating			✓			
Motivation to self-manage	✓	✓	✓	✓	✓	✓
Coping with embarrassment and shame	✓	✓	✓	✓		✓
Confidence to self-manage	✓	✓	✓	✓	✓	✓
Using physical activity to manage PCOS	✓	✓	✓			
Trust in health professionals	✓		✓	✓	✓	✓
Coping with anxiety and fear	✓	✓	✓	✓	✓	✓
Prioritizing your own needs	✓	✓	✓	✓	✓	✓
Setting clear self-management goals	✓	✓	✓	✓	✓	✓
Not giving up on self-management	✓	✓	✓	✓	✓	✓
Coping with frustration and anger	✓	✓	✓	✓	✓	✓
Coping with loneliness and isolation	✓	✓	✓	✓	✓	✓
Finding a physical activity that is enjoyable		✓				
Skills to communicate with health professionals	✓			✓	✓	
Monitoring your menstrual cycle	✓	✓		✓		✓
How to keep trying to self-manage	✓	✓	✓	✓	✓	✓
Setting realistic goals	✓	✓	✓	✓	✓	✓
Realistic expectations of the body	✓			✓		
Getting social support	✓	✓	✓	✓	✓	✓

Choosing Theory- and Evidence-Based Intervention Components to Address Modifiable Antecedents of Self-Management

The HOPE program framework used to develop the PCOS intervention includes the following self-management intervention components: information about available resources, safety netting, training and rehearsal to communicate with health care professionals, training and rehearsal in psychological strategies, social support, and lifestyle advice and support [69]. Below, we outline how specific intervention content was

selected to address the antecedents identified in the logic model for PCOS self-management.

Information and Activities to Target Knowledge and Understanding for Self-Management

Women with PCOS have unmet information needs [63,70-72] and may lack knowledge of how to manage their condition, for example, how to eat well to manage insulin resistance [33,73]. Unmet information needs may adversely impact self-management, including adherence to treatment [26,28,32,74,75]. PCOS-specific information is valued by

patients with PCOS and may address unmet psychosocial needs [76-78], potentially enhancing understanding, reducing anxiety, and promoting quality of life [79]. There is a plethora of information sources available on the web, of varying quality, making it difficult for women with PCOS to select trustworthy material [71,80-83]. Signposting to trustworthy information sources may support patient activation and self-management. In the prototype intervention, factual information is provided about PCOS, including androgen excess and food intake, blood sugar and insulin resistance, eating well, and managing weight.

The needs assessment and previous research [84,85] indicate women may have concerns about the long-term health sequelae of PCOS. Motivation to adopt healthy lifestyles may be impacted by perceptions of the health risks associated with PCOS [28]. In the prototype intervention, content is provided on focusing on future health and ways to manage emerging health concerns and worries. Information about specialist health professionals, the range of support, and some potential treatment options is designed to empower participants to be active partners in their health care. The intervention seeks to empower participants to engage in health protective behaviors, for example, exercise, healthy eating, self-monitoring of their health, managing worries to alleviate health anxiety, and future help-seeking as any new health issues arise. Links to further information and resources are provided, for example, Verity (a UK PCOS charity), the NHS Choices website, the NHS Improving Access to Psychological Therapies service, and the AskPCOS app [86].

Goal Setting and Feedback to Target Self-Management Motivation and Behavior

Women with PCOS may struggle to achieve the goals they set for lifestyle change [27], may lack the ability to identify and resolve barriers [32], experience tiredness, feel unrewarded, or have depressive and defeating thoughts that act as barriers to achieving their goals [29]. Goal setting is a widely used and effective component of self-management support [87,88]. Goal-oriented care, emphasizing patient priorities and values, may be particularly appropriate for patients with chronic or multifaceted health concerns [89]. Goal-setting theory and research recommend paying attention to multiple goal factors and multiple phases in the goal process [90].

Goal setting and solution-focused goal feedback are included in every session of the prototype intervention, with weekly and long-term goals chosen by participants themselves based on their personal priorities and values rather than set or recommended by program facilitators. The goal-setting and feedback processes are facilitated by peer facilitators, with attention to goal difficulty, goal specificity, goal proximity, goal commitment, and solution-focused feedback.

Psychoeducation and Activities to Target Emotions

Women with PCOS are prone to higher perceived stress [91], and stress may also impact women with PCOS differently and have an impact on the physiology of the condition [92,93]. Stress may be a barrier to lifestyle change [32]. Mindfulness-based stress reduction activities have been effective in reducing stress, depressive, and anxiety symptoms in PCOS

[94] and in increasing self-efficacy for physical activity and nutrition behaviors [95]. Physical activity has well-recognized benefits for mood and perceived stress [96,97], including in women with PCOS [98,99]. In the prototype intervention, content is provided on managing stress, including mindfulness, soothing rhythm breathing, guided imagery, and “get active, feel good.” Because interviews with health professionals during the needs assessment suggested that some women with PCOS may exercise in dysfunctional ways in order to lose weight, the PCOS prototype intervention does not promote exercise for weight loss per se but rather for stress management and general well-being.

Psychological comorbidities may be a barrier to lifestyle change [32]. Interventions using aspects of cognitive behavioral therapy (CBT) have shown promise for improving fatigue, quality of life, weight loss, and depressive symptoms in women with PCOS [100-103]. In the prototype intervention, CBT-informed content is provided on managing common unhelpful thinking patterns. Compassionate mind approaches (sometimes referred to as part of a “third wave” of CBT) are particularly relevant to disordered eating, emotional eating, and weight management [104-107]. In the prototype intervention, a compassionate mind approach is taken to eating well, including eating mindfully, overeating, binge eating, and self-soothing.

Self-compassion activities, compassionate mind training, and compassion-focused therapy have been demonstrated to be particularly beneficial in improving anxiety, depression, shame, and self-criticism [106,108-111]. These issues have been identified as common in populations with PCOS. In the prototype intervention, content is provided on self-compassion, including, for example, compassion for perceived flaws, toward feelings of embarrassment or shame, and “getting to know your inner critic.”

Women with PCOS may have reduced relational and marital satisfaction [17,112], sexual satisfaction, function, and sense of sexual attractiveness [16,113-119]. Body dissatisfaction may be a barrier to lifestyle change [28]. The prototype intervention discusses and seeks to normalize the topic of common body changes and associated distress, for example, acne, alopecia, hirsutism, obesity, and associated low self-esteem, frustration, and depression, which have been identified in previous research [84,120-123], and in the needs assessment. Content is provided on common body changes in PCOS and associated difficult emotions. The potential impact of PCOS on intimate relationships and sexuality is explored, along with suggestions for ways to cope and adjust.

The population with PCOS is diverse, including women who will be more or less concerned about visible or invisible body changes. Interventions may empower them to respond and adjust in ways that are personally appropriate, including accepting changes, making adaptations, or seeking treatment, for example, for obesity or hirsutism. Previous research, including the needs assessment, indicates that embarrassment or shame may lead women to conceal the extent of their bodily changes, even from health professionals [124-127]. In the prototype intervention, content is provided on responding to change, including acceptance, treatments and adaptations, and overcoming

embarrassment to get help for body changes. The PCOS intervention takes an autonomy or body acceptance approach [128,129]. Unrealistic female body standards and body-positive activism are discussed in the program materials.

Women may struggle to manage and control their PCOS symptoms, especially if they have comorbidities, sometimes feeling controlled by their condition [84]. Motivational imagery interventions are widely used in sports psychology, with benefits for motor performance, motivational outcomes, and affective outcomes [130] and found to be motivating by a number of different populations, including people trying to manage their weight or type 2 diabetes [131,132]. Emotional mental imagery interventions have shown promise for reducing anxiety and depression [133,134]. Prospective (future-focused) mental imagery interventions are particularly relevant to fostering optimism in people with depression [135]. In the prototype intervention, content is provided on life priorities and motivational imagery—“keeping PCOS in its place”—and future-focused mental imagery.

Positive psychology interventions, such as character strengths and gratitude diaries, which focus on function rather than dysfunction, have shown promise in treating anxiety, depression, low mood, and low self-esteem and in promoting positive well-being [136-138]. In the prototype intervention, content is provided on maximizing psychological resources, for example, by focusing on character strengths and gratitude diaries rather than focusing purely on psychological deficits and dysfunctions.

Activities for Development of Self-Management Communication Skills

Being able to communicate the need for practical and social support is essential for effective self-management. Communicating with friends, family, peers, and health professionals may be particularly difficult for women with PCOS because of its sometimes visible, sometimes invisible nature and associated taboos and stigma [139-142]. In the prototype intervention, content is provided on communication, including communicating concerns with friends, family, peers, and health professionals.

The intervention explicitly acknowledges the issue that some women with PCOS may lack trust in, or feel dismissed or stigmatized by, health professionals [70,71,143-147]. Some health professionals treating PCOS recognize that “lifestyle change,” especially around weight, is a sensitive topic [148], but some patients report a lack of trust in and perceived lack of empathy from health professionals. Intervention materials in the prototype explore and deconstruct health communication around weight to foster shared understanding and trust.

People with long-term health conditions need a range of knowledge and skills to navigate health care systems and participate actively in consultations and care [149]. In the prototype intervention, content is provided on maximizing support from health services and health professionals, including health care specialists who treat PCOS, treatments, “why it may sometimes sound like health professionals are being preachy or judgemental,” summarizing concerns and requesting a

referral, shared agenda setting at health care appointments, and communicating clearly and assertively with health professionals.

Building on Therapeutic Peer Group Factors and Collective Advocacy

Women with PCOS are interested in group education interventions [150]. Group psychosocial and psychoeducational interventions provide particular therapeutic factors, for example, instillation of hope, universality, imparting of information, and opportunities for altruism and catharsis [151]. A lack of social support may be a barrier to lifestyle change [32,33]. Group and peer support, provided face-to-face or on the web, have been beneficial for those living with PCOS [76,78,152-154]. Peers delivering interventions may be well placed to express empathy and to act as realistic role models, supporting self-management [155-157].

Peer group factors are emphasized and facilitated throughout the prototype PCOS intervention, including, for example, self-management, “your PCOS journey,” getting peer support, open space forums, support from health professionals, peers, and the UK PCOS charity, and signposting to ongoing participation with PCOS-related groups and networks. The intervention is delivered in a web-based group format with secure digital social sharing features, for example, a gratitude wall, hopes and dreams, goal sharing, and delivery by trained peer facilitators who themselves had PCOS. Group delivery allows the intervention to be made available to multiple participants, saving time and resources for facilitators.

Improving health care access and outcomes for PCOS is not simply a matter of individual patient assertiveness. Collective collaborative action between patients, health professionals, and powerful others is needed to bring about change. In the prototype intervention, content acknowledges the limits of personal assertiveness and emphasizes the value of collective action. For example, we signpost to activism by Verity [158] and other women’s health organizations.

Modular Web-Based Format for Accessibility And Scalability

Digital health interventions offer considerable scope for accessibility and scalability [159]. The prototype PCOS intervention is designed to be delivered digitally through a secure social platform developed by the social enterprise community interest company Hope for the Community (H4C) [160]. The social enterprise company hosts the intervention and has a track record of scaling up the existing HOPE interventions for a range of commissioners. The H4C web-based intervention platform allows peers to support each other and engage in synchronous or asynchronous therapeutic activities in a web-based space without the logistical and practical difficulties of travel and finding venues and times suitable for all.

Program Specification

Textbox 1 shows the content of the 6-week prototype intervention program. Solution-focused goal setting and feedback, open forum discussions, and further resources are provided in every session.

The H4C team uploaded the additional content and created a working prototype intervention that was checked and tested, ready for a pilot study with women living with PCOS.

Textbox 1. Content of polycystic ovary syndrome (PCOS) intervention.

Session 1: Instilling HOPE for PCOS

- Welcome and introductions
- Responsibilities and ground rules
- Instilling HOPE
- Diaphragmatic breathing
- Gratitude diary
- Your PCOS journey
- Support from health professionals, peers, and Verity (UK PCOS charity)
- PCOS basics: androgen excess & insulin resistance
- Test your PCOS basics: quiz
- Factual information about PCOS
- Self-management
- Self-compassion

Session 2: Managing the stress of PCOS

- Gratitude diary
- Managing stress
- Mindfulness
- Physical activity for stress management: “get active, feel good”
- Managing common unhelpful thinking patterns (cognitive behavioral therapy [CBT])
- Mindfulness: and am I doing this “right”?
- Why self-compassionate mindfulness?
- Compassion-focused therapy

Session 3: Feeding your mind and body well

- Gratitude diary
- Eating well in PCOS: role of food intake, blood sugar, and insulin
- Why being insulin resistant is a problem for the whole body
- Why it may sometimes sound like health professionals are being preachy or judgmental
- Eating well without depriving yourself, losing weight in PCOS
- Eating mindfully to eat well in PCOS
- Overeating and binge eating in PCOS: some helpful tips for reducing the chances of overeating
- Feeding your mind and body well
- Feeding your mind: three systems regulating our emotions
- Ways to soothe yourself without over- or undereating
- Getting to know your inner critic, developing a compassionate ideal

Session 4: Body image, intimacy, and close relationships

- Gratitude diary
- Body changes, sexuality, and intimacy
- Communication
- Common body changes in PCOS
- Difficult emotions that can come with body changes
- Getting ready to be self-compassionate
- Compassion for your perceived flaws

- Overcoming embarrassment to get help for body changes
- Getting ready to be self-compassionate toward feelings of embarrassment or shame
- Responding to change: acceptance, treatments, and adaptations
- Treatments

Session 5: Staying healthy with PCOS

- Gratitude diary
- Focusing on your future health
- Ways to manage emerging health concerns and worries about your future health
- Getting peer support
- Maximizing your psychological resources
- Maximize the support you get from health services and health professionals
- Health care specialists who treat PCOS
- Activity: Summarizing concerns and requesting a referral
- Communicating clearly and assertively with health professionals
- Activity: Shared agenda setting at health care appointments
- When communicating clearly and asking assertively do not get you what you want

Session 6: Keeping PCOS in its place—your strengths and life goals

- Gratitude diary
- Character strengths
- Life priorities
- Motivational imagery
- Sharing our successes
- Self-compassion
- Activity: self-compassionate letter
- Signposting to ongoing participation with PCOS related groups and networks

Discussion

Principal Results

We cocreatively identified and prioritized barriers to self-management and psychological well-being to adapt a successful web-based self-management program and tailor it for the needs of adult women with PCOS. We developed a web-based prototype program for the PCOS program, ready for testing with this population.

Comparison With Previous Work

Women with PCOS value specialized, integrated, evidence-based, patient-centered health care services, ideally codeveloped with consumers and health professionals [34,35]. The new HOPE PCOS intervention has been codeveloped by combining input from patients, patients with PCOS' advocates, and health care professionals. It is a comprehensive intervention integrating education and empowerment with lifestyle management, cognitive behavioral tools, and peer support, ready to be delivered by trained peer facilitators or codelivered by peers and health care professionals.

Developed following MRC guidance for the development of complex interventions [45,47], the intervention is evidence-based, underpinned by relevant theory, and designed to support a collaborative approach to care. Subject to evaluation, the new intervention could be integrated as part of PCOS services to support self-management and the model of collaborative, patient-centered health care advocated by international guidelines [4,161].

The intervention deploys an existing secure web-based social platform that has been used successfully to scale up other self-management support programs for other populations and conditions [40,44]. The multicomponent and modular structure of the program offers flexibility in adapting it further as new clinical recommendations and patient information emerge. The intervention is therefore well placed to be delivered and evaluated at scale.

The HOPE PCOS intervention is designed to support self-management and promote psychological well-being, rather than as a behavior change intervention per se. Since we started the process of cocreating the HOPE PCOS intervention, a different team has undertaken development work for a behavior change lifestyle intervention using a different intervention design

model [28,31-33]. That work has not yet, to our knowledge, resulted in a prototype intervention. However, the findings from the needs assessment work conducted by that team for their lifestyle intervention concur considerably with our own needs assessment results, showing that women living with PCOS may often experience barriers of capability, opportunity, and motivation, for example, a lack of credible information, difficulty managing multiple health conditions, limited access to resources, adequate social support, and issues such as health expectancies and emotional eating affecting their motivation to engage in lifestyle change [33].

Limitations

The current HOPE PCOS intervention is based on a needs assessment conducted with adult women. As part of the iterative cocreation process, further needs assessments may be required to adapt and tailor future versions of the intervention for other populations, for example, adolescents with PCOS, as concerns, distress, and intervention format preferences may differ [162]. There is scope to develop variants of the intervention for specific adult populations, for example, perimenopausal, menopausal, or postmenopausal women with PCOS who may have specific concerns [163-165]. The intervention might also be tailored to support trans and nonbinary people with PCOS, those with particular concerns such as weight management, comorbid conditions, or those actively trying to conceive. More cocreation and development work could be done to ensure the intervention is culturally appropriate. The intervention is intended to provide extra support and not to bypass what is recommended by a clinician. Women with PCOS are not advised to rely fully on this self-management intervention and are advised to consult a clinician as appropriate.

Cocreative intervention development is an iterative process, and, in addition to tailoring the HOPE PCOS intervention for different populations, future iterations may need to develop new content or place greater emphasis on some components, depending on how participants and health professionals evaluate the program. If consensus emerges about specific target behaviors for self-management in PCOS, it may be necessary in the future to adapt the intervention to promote specific

behavior change. For example, the current content promoting physical activity could be modified and refined to promote a target level of physical activity, or the current material on healthy eating could be modified to promote specific changes in eating behavior.

Although the prototype intervention has been collaboratively co-designed to support self-management and psychological well-being, further feasibility research is needed with patients with PCOS using the program. This should evaluate the program's acceptability as well as its impact on key outcomes such as measures of self-management, depression, anxiety, and psychological well-being. Future work is also needed to assess the intervention's scalability, cost-effectiveness, and suitability for integration with standard care.

Conclusions

The development of the novel HOPE PCOS intervention contributes to ongoing efforts to support patients with long-term conditions to self-manage effectively and is, to our knowledge, the first such program for patients with PCOS. This study has demonstrated that comprehensive intervention programs can be codeveloped with patients with PCOS, patient advocates, and health care professionals to address multiple barriers to self-management and psychological well-being. A person-centered, holistic approach, organized around the self-reported needs and priorities of patients, may produce interventions that complement services provided by health care professionals and patient advocacy and support organizations.

This study demonstrates that the use of a remote digital platform with preloaded, evidence-based intervention content may offer economies of scale in that complex self-management support interventions might be delivered to many patients in parallel, potentially saving clinic resources for one-to-one care. A key message for those working to develop lifestyle or self-management support interventions is the potential value of adapting an existing program and reusing existing digital infrastructure to provide a tailored intervention without the additional resource implications of developing an entire intervention from scratch.

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Data Availability

The data sets generated or analyzed during this study are not publicly available due to participants' consent being given for anonymized extracts only (not whole transcripts) to be used in published reports, but data are available from the corresponding author upon reasonable request.

Conflicts of Interest

AT is the co-inventor of the original HOPE Program, co-founder, and nonexecutive director of Hope For The Community (H4C).

References

1. Safiri S, Noori M, Nejadghaderi SA, Karamzad N, Carson-Chahhoud K, Sullman MJM, et al. Prevalence, incidence and years lived with disability due to polycystic ovary syndrome in 204 countries and territories, 1990-2019. *Hum Reprod.* 2022;37(8):1919-1931. [FREE Full text] [doi: [10.1093/humrep/deac091](https://doi.org/10.1093/humrep/deac091)] [Medline: [35586937](https://pubmed.ncbi.nlm.nih.gov/35586937/)]
2. Gilbert EW, Tay CT, Hiam DS, Teede HJ, Moran LJ. Comorbidities and complications of polycystic ovary syndrome: an overview of systematic reviews. *Clin Endocrinol (Oxf).* 2018;89(6):683-699. [FREE Full text] [doi: [10.1111/cen.13828](https://doi.org/10.1111/cen.13828)] [Medline: [30099747](https://pubmed.ncbi.nlm.nih.gov/30099747/)]
3. Bozdog G, Mumusoglu S, Zengin D, Karabulut E, Yildiz BO. The prevalence and phenotypic features of polycystic ovary syndrome: a systematic review and meta-analysis. *Hum Reprod.* 2016;31(12):2841-2855. [FREE Full text] [doi: [10.1093/humrep/dew218](https://doi.org/10.1093/humrep/dew218)] [Medline: [27664216](https://pubmed.ncbi.nlm.nih.gov/27664216/)]
4. Teede H, Tay CH, Laven J, Dokras A, Moran L, Piltonen T, et al. International evidence-based guideline for the assessment and management of polycystic ovary syndrome. Centre for Research Excellence in PCOS. 2018. URL: <https://www.eshre.eu/Guidelines-and-Legal/Guidelines/Polycystic-Ovary-Syndrome> [accessed 2024-01-31]
5. Cooney LG, Lee I, Sammel MD, Dokras A. High prevalence of moderate and severe depressive and anxiety symptoms in polycystic ovary syndrome: a systematic review and meta-analysis. *Hum Reprod.* 2017;32(5):1075-1091. [FREE Full text] [doi: [10.1093/humrep/dex044](https://doi.org/10.1093/humrep/dex044)] [Medline: [28333286](https://pubmed.ncbi.nlm.nih.gov/28333286/)]
6. Castelo-Branco C, Naumova I. Quality of life and sexual function in women with polycystic ovary syndrome: a comprehensive review. *Gynecol Endocrinol.* 2020;36(2):96-103. [doi: [10.1080/09513590.2019.1670788](https://doi.org/10.1080/09513590.2019.1670788)] [Medline: [31559883](https://pubmed.ncbi.nlm.nih.gov/31559883/)]
7. Tay CT, Teede HJ, Loxton D, Kulkarni J, Joham AE. Psychiatric comorbidities and adverse childhood experiences in women with self-reported polycystic ovary syndrome: an Australian population-based study. *Psychoneuroendocrinology.* 2020;116:104678. [doi: [10.1016/j.psyneuen.2020.104678](https://doi.org/10.1016/j.psyneuen.2020.104678)] [Medline: [32361187](https://pubmed.ncbi.nlm.nih.gov/32361187/)]
8. Yin X, Ji Y, Chan CLW, Chan CHY. The mental health of women with polycystic ovary syndrome: a systematic review and meta-analysis. *Arch Womens Ment Health.* 2021;24(1):11-27. [doi: [10.1007/s00737-020-01043-x](https://doi.org/10.1007/s00737-020-01043-x)] [Medline: [32514730](https://pubmed.ncbi.nlm.nih.gov/32514730/)]
9. Basirat Z, Faramarzi M, Chehrizi M, Amiri M, Ghofrani F, Tajalli Z. Differences between infertile women with and without PCOS in terms of anxiety, coping styles, personality traits, and social adjustment: a case-control study. *Arch Gynecol Obstet.* 2020;301(2):619-626. [doi: [10.1007/s00404-019-05391-7](https://doi.org/10.1007/s00404-019-05391-7)] [Medline: [31776708](https://pubmed.ncbi.nlm.nih.gov/31776708/)]
10. Teede H, Deeks A, Moran L. Polycystic ovary syndrome: a complex condition with psychological, reproductive and metabolic manifestations that impacts on health across the lifespan. *BMC Med.* 2010;8:41. [FREE Full text] [doi: [10.1186/1741-7015-8-41](https://doi.org/10.1186/1741-7015-8-41)] [Medline: [20591140](https://pubmed.ncbi.nlm.nih.gov/20591140/)]
11. Dokras A, Stener-Victorin E, Yildiz BO, Li R, Ottey S, Shah D, et al. Androgen excess- Polycystic Ovary Syndrome Society: position statement on depression, anxiety, quality of life, and eating disorders in polycystic ovary syndrome. *Fertil Steril.* 2018;109(5):888-899. [FREE Full text] [doi: [10.1016/j.fertnstert.2018.01.038](https://doi.org/10.1016/j.fertnstert.2018.01.038)] [Medline: [29778388](https://pubmed.ncbi.nlm.nih.gov/29778388/)]
12. Jeanes YM, Reeves S, Gibson EL, Piggott C, May VA, Hart KH. Binge eating behaviours and food cravings in women with polycystic ovary syndrome. *Appetite.* 2017;109:24-32. [doi: [10.1016/j.appet.2016.11.010](https://doi.org/10.1016/j.appet.2016.11.010)] [Medline: [27825940](https://pubmed.ncbi.nlm.nih.gov/27825940/)]
13. Kolhe JV, Chhipa AS, Butani S, Chavda V, Patel SS. PCOS and depression: common links and potential targets. *Reprod Sci.* 2022;29(11):3106-3123. [doi: [10.1007/s43032-021-00765-2](https://doi.org/10.1007/s43032-021-00765-2)] [Medline: [34642910](https://pubmed.ncbi.nlm.nih.gov/34642910/)]
14. Lee I, Cooney LG, Saini S, Smith ME, Sammel MD, Allison KC, et al. Increased risk of disordered eating in polycystic ovary syndrome. *Fertil Steril.* 2017;107(3):796-802. [FREE Full text] [doi: [10.1016/j.fertnstert.2016.12.014](https://doi.org/10.1016/j.fertnstert.2016.12.014)] [Medline: [28104244](https://pubmed.ncbi.nlm.nih.gov/28104244/)]
15. Moran LJ, Brown WJ, McNaughton SA, Joham AE, Teede HJ. Weight management practices associated with PCOS and their relationships with diet and physical activity. *Hum Reprod.* 2017;32(3):669-678. [FREE Full text] [doi: [10.1093/humrep/dew348](https://doi.org/10.1093/humrep/dew348)] [Medline: [28069732](https://pubmed.ncbi.nlm.nih.gov/28069732/)]
16. Pastoor H, Timman R, de Klerk C, Bramer WM, Laan ET, Laven JS. Sexual function in women with polycystic ovary syndrome: a systematic review and meta-analysis. *Reprod Biomed Online.* 2018;37(6):750-760. [FREE Full text] [doi: [10.1016/j.rbmo.2018.09.010](https://doi.org/10.1016/j.rbmo.2018.09.010)] [Medline: [30420168](https://pubmed.ncbi.nlm.nih.gov/30420168/)]
17. De Frène V, Verhofstadt L, Loeys T, Stuyver I, Buysse A, De Sutter P. Sexual and relational satisfaction in couples where the woman has polycystic ovary syndrome: a dyadic analysis. *Hum Reprod.* 2015;30(3):625-631. [FREE Full text] [doi: [10.1093/humrep/deu342](https://doi.org/10.1093/humrep/deu342)] [Medline: [25534460](https://pubmed.ncbi.nlm.nih.gov/25534460/)]
18. Atkinson L, Kite C, McGregor G, James T, Clark CCT, Randeva HS, et al. Uncertainty, anxiety and isolation: experiencing the COVID-19 pandemic and lockdown as a woman with Polycystic Ovary Syndrome (PCOS). *J Pers Med.* 2021;11(10):952. [FREE Full text] [doi: [10.3390/jpm11100952](https://doi.org/10.3390/jpm11100952)] [Medline: [34683093](https://pubmed.ncbi.nlm.nih.gov/34683093/)]
19. Hart R, Doherty DA. The potential implications of a PCOS diagnosis on a woman's long-term health using data linkage. *J Clin Endocrinol Metab.* 2015;100(3):911-919. [FREE Full text] [doi: [10.1210/jc.2014-3886](https://doi.org/10.1210/jc.2014-3886)] [Medline: [25532045](https://pubmed.ncbi.nlm.nih.gov/25532045/)]
20. Allen LA, Shrikrishnapalasuriyar N, Rees DA. Long-term health outcomes in young women with polycystic ovary syndrome: a narrative review. *Clin Endocrinol (Oxf).* 2022;97(2):187-198. [FREE Full text] [doi: [10.1111/cen.14609](https://doi.org/10.1111/cen.14609)] [Medline: [34617616](https://pubmed.ncbi.nlm.nih.gov/34617616/)]
21. Kutenae MA, Amirjani S, Asemi Z, Taghavi SA, Allan H, Kamalnadian SN, et al. The impact of depression, self-esteem, and body image on sleep quality in patients with PCOS: a cross-sectional study. *Sleep Breath.* 2020;24(3):1027-1034. [doi: [10.1007/s11325-019-01946-9](https://doi.org/10.1007/s11325-019-01946-9)] [Medline: [31630370](https://pubmed.ncbi.nlm.nih.gov/31630370/)]

22. Helvacı N, Karabulut E, Demir AU, Yildiz BO. Polycystic ovary syndrome and the risk of obstructive sleep apnea: a meta-analysis and review of the literature. *Endocr Connect*. 2017;6(7):437-445. [FREE Full text] [doi: [10.1530/EC-17-0129](https://doi.org/10.1530/EC-17-0129)] [Medline: [28739562](https://pubmed.ncbi.nlm.nih.gov/28739562/)]
23. Kahal H, Kyrou I, Uthman OA, Brown A, Johnson S, Wall PDH, et al. The prevalence of obstructive sleep apnoea in women with polycystic ovary syndrome: a systematic review and meta-analysis. *Sleep Breath*. 2020;24(1):339-350. [FREE Full text] [doi: [10.1007/s11325-019-01835-1](https://doi.org/10.1007/s11325-019-01835-1)] [Medline: [31111411](https://pubmed.ncbi.nlm.nih.gov/31111411/)]
24. Schoretsanitis G, Gastaldon C, Kalaitzopoulos DR, Ochslein-Koelble N, Barbui C, Seifritz E. Polycystic ovary syndrome and postpartum depression: a systematic review and meta-analysis of observational studies. *J Affect Disord*. 2022;299:463-469. [doi: [10.1016/j.jad.2021.12.044](https://doi.org/10.1016/j.jad.2021.12.044)] [Medline: [34952106](https://pubmed.ncbi.nlm.nih.gov/34952106/)]
25. Mayor S. Women with polycystic ovary syndrome admitted to hospital twice as often, study finds. *BMJ*. 2015;350:h539. [doi: [10.1136/bmj.h539](https://doi.org/10.1136/bmj.h539)] [Medline: [25636662](https://pubmed.ncbi.nlm.nih.gov/25636662/)]
26. Parker M, Warren A, Nair S, Barnard M. Adherence to treatment for polycystic ovarian syndrome: a systematic review. *PLoS One*. 2020;15(2):e0228586. [FREE Full text] [doi: [10.1371/journal.pone.0228586](https://doi.org/10.1371/journal.pone.0228586)] [Medline: [32053629](https://pubmed.ncbi.nlm.nih.gov/32053629/)]
27. Arentz S, Smith CA, Abbott J, Bensoussan A. Perceptions and experiences of lifestyle interventions in women with Polycystic Ovary Syndrome (PCOS), as a management strategy for symptoms of PCOS. *BMC Womens Health*. 2021;21(1):107. [FREE Full text] [doi: [10.1186/s12905-021-01252-1](https://doi.org/10.1186/s12905-021-01252-1)] [Medline: [33731099](https://pubmed.ncbi.nlm.nih.gov/33731099/)]
28. Ee C, Pirotta S, Mousa A, Moran L, Lim S. Providing lifestyle advice to women with PCOS: an overview of practical issues affecting success. *BMC Endocr Disord*. 2021;21(1):234. [FREE Full text] [doi: [10.1186/s12902-021-00890-8](https://doi.org/10.1186/s12902-021-00890-8)] [Medline: [34814919](https://pubmed.ncbi.nlm.nih.gov/34814919/)]
29. Lim S, Smith CA, Costello MF, MacMillan F, Moran L, Ee C. Barriers and facilitators to weight management in overweight and obese women living in Australia with PCOS: a qualitative study. *BMC Endocr Disord*. 2019;19(1):106. [FREE Full text] [doi: [10.1186/s12902-019-0434-8](https://doi.org/10.1186/s12902-019-0434-8)] [Medline: [31647000](https://pubmed.ncbi.nlm.nih.gov/31647000/)]
30. Moran LJ, Tan ZQ, Bayer S, Boyle JA, Robinson T, Lim SS. Perspectives of allied health professionals on implementation of the lifestyle polycystic ovary syndrome guidelines: a qualitative study. *J Acad Nutr Diet*. 2022;122(7):1305-1316. [doi: [10.1016/j.jand.2021.11.013](https://doi.org/10.1016/j.jand.2021.11.013)] [Medline: [34800697](https://pubmed.ncbi.nlm.nih.gov/34800697/)]
31. Pirotta S, Joham AE, Moran LJ, Skouteris H, Lim SS. Implementation of the polycystic ovary syndrome guidelines: a mixed method study to inform the design and delivery of a lifestyle management program for women with polycystic ovary syndrome. *Nutr Diet*. 2021;78(5):476-486. [doi: [10.1111/1747-0080.12670](https://doi.org/10.1111/1747-0080.12670)] [Medline: [33876532](https://pubmed.ncbi.nlm.nih.gov/33876532/)]
32. Pirotta S, Joham AJ, Moran LJ, Skouteris H, Lim SS. Implementation of evidence-based PCOS lifestyle management guidelines: perceived barriers and facilitators by consumers using the theoretical domains framework and COM-B model. *Patient Educ Couns*. 2021;104(8):2080-2088. [doi: [10.1016/j.pec.2021.01.036](https://doi.org/10.1016/j.pec.2021.01.036)] [Medline: [33581970](https://pubmed.ncbi.nlm.nih.gov/33581970/)]
33. Pirotta S, Joham AE, Moran LJ, Skouteris H, Lim SS. Informing a PCOS lifestyle program: mapping behavior change techniques to barriers and enablers to behavior change using the theoretical domains framework. *Semin Reprod Med*. 2021;39(3-04):143-152. [doi: [10.1055/s-0041-1735456](https://doi.org/10.1055/s-0041-1735456)] [Medline: [34433214](https://pubmed.ncbi.nlm.nih.gov/34433214/)]
34. Tay CT, Pirotta S, Teede HJ, Moran LJ, Robinson T, Skouteris H, et al. Polycystic ovary syndrome models of care: a review and qualitative evaluation of a guideline-recommended integrated care. *Semin Reprod Med*. 2021;39(3-04):133-142. [doi: [10.1055/s-0041-1727191](https://doi.org/10.1055/s-0041-1727191)] [Medline: [34187051](https://pubmed.ncbi.nlm.nih.gov/34187051/)]
35. Tay CT, Moran LJ, Wijayarathne CN, Redman LM, Norman RJ, Teede HJ, et al. Integrated model of care for polycystic ovary syndrome. *Semin Reprod Med*. 2018;36(1):86-94. [doi: [10.1055/s-0038-1667310](https://doi.org/10.1055/s-0038-1667310)] [Medline: [30189456](https://pubmed.ncbi.nlm.nih.gov/30189456/)]
36. Hermanns N, Ehrmann D, Finke-Groene K, Kulzer B. Trends in diabetes self-management education: where are we coming from and where are we going? A narrative review. *Diabet Med*. 2020;37(3):436-447. [FREE Full text] [doi: [10.1111/dme.14256](https://doi.org/10.1111/dme.14256)] [Medline: [32017188](https://pubmed.ncbi.nlm.nih.gov/32017188/)]
37. Turner A, Anderson JK, Wallace LM, Bourne C. An evaluation of a self-management program for patients with long-term conditions. *Patient Educ Couns*. 2015;98(2):213-219. [FREE Full text] [doi: [10.1016/j.pec.2014.08.022](https://doi.org/10.1016/j.pec.2014.08.022)] [Medline: [25441096](https://pubmed.ncbi.nlm.nih.gov/25441096/)]
38. Kosmala-Anderson JP, Wallace LM, Turner A, Bourne C. Self-reported effects of attending the Health Foundation's Co-creating health self-management programme for patients with type 2 diabetes mellitus in London, England. *Arch Med Sci*. 2014;10(4):773-781. [FREE Full text] [doi: [10.5114/aoms.2014.44869](https://doi.org/10.5114/aoms.2014.44869)] [Medline: [25276164](https://pubmed.ncbi.nlm.nih.gov/25276164/)]
39. Schulman-Green D, Jaser S, Martin F, Alonzo A, Grey M, McCorkle R, et al. Processes of self-management in chronic illness. *J Nurs Scholarsh*. 2012;44(2):136-144. [FREE Full text] [doi: [10.1111/j.1547-5069.2012.01444.x](https://doi.org/10.1111/j.1547-5069.2012.01444.x)] [Medline: [22551013](https://pubmed.ncbi.nlm.nih.gov/22551013/)]
40. Martin F, Wright H, Moody L, Whiteman B, McGillion M, Clyne W, et al. Help to overcome problems effectively for cancer survivors: development and evaluation of a digital self-management program. *J Med Internet Res*. 2020;22(5):e17824. [FREE Full text] [doi: [10.2196/17824](https://doi.org/10.2196/17824)] [Medline: [32209529](https://pubmed.ncbi.nlm.nih.gov/32209529/)]
41. Turner A, Martin F. The development of a hope-based self-management intervention. In: Matz E, editor. *Promoting Self-Management of Chronic Health Conditions: Theories and Practice*. New York. Oxford University Press; 2017;58-79.
42. Anderson JK, Turner A, Clyne W. Development and feasibility of the Help to Overcome Problems Effectively (HOPE) self-management intervention for people living with multiple sclerosis. *Disabil Rehabil*. 2017;39(11):1114-1121. [doi: [10.1080/09638288.2016.1181211](https://doi.org/10.1080/09638288.2016.1181211)] [Medline: [27278670](https://pubmed.ncbi.nlm.nih.gov/27278670/)]

43. Martin F, Clyne W, Pearce G, Turner A. Self-management support intervention for parents of children with developmental disorders: the role of gratitude and hope. *J Child Fam Stud*. 2019;28(4):980-992. [FREE Full text] [doi: [10.1007/s10826-018-01308-1](https://doi.org/10.1007/s10826-018-01308-1)]
44. Turner A, Grant-Pearce C, Whiteman B. Developing and evaluating a web-based self-management programme: iHOPE for cancer survivors. Final report to Macmillan cancer support. Coventry University. 2017. URL: <https://www.coventry.ac.uk/research/research-directories/completed-projects/2015/ihope/> [accessed 2024-01-31]
45. Craig P, Dieppe P, Macintyre S, Michie S, Nazareth I, Petticrew M, et al. Medical Research Council Guidance. Developing and evaluating complex interventions: the new Medical Research Council guidance. *BMJ*. 2008;337:a1655. [FREE Full text] [doi: [10.1136/bmj.a1655](https://doi.org/10.1136/bmj.a1655)] [Medline: [18824488](https://pubmed.ncbi.nlm.nih.gov/18824488/)]
46. O' Cathain A, Croot L, Duncan E, Rousseau N, Sworn K, Turner KM, et al. Guidance on how to develop complex interventions to improve health and healthcare. *BMJ Open*. 2019;9(8):e029954. [FREE Full text] [doi: [10.1136/bmjopen-2019-029954](https://doi.org/10.1136/bmjopen-2019-029954)] [Medline: [31420394](https://pubmed.ncbi.nlm.nih.gov/31420394/)]
47. Skivington K, Matthews L, Simpson SA, Craig P, Baird J, Blazeby JM, et al. Framework for the development and evaluation of complex interventions: gap analysis, workshop and consultation-informed update. *Health Technol Assess*. 2021;25(57):1-132. [FREE Full text] [doi: [10.3310/hta25570](https://doi.org/10.3310/hta25570)] [Medline: [34590577](https://pubmed.ncbi.nlm.nih.gov/34590577/)]
48. Percy C. 'Hope for PCOS': co-creation of an online self-management peer support programme for polycystic ovary syndrome. In: Poster Presentation. 20219. Presented at: 33rd Annual Conference of the European Health Psychology Society; September 03-07, 2019, 20219; Dubrovnik, Croatia.
49. Noar SM, Zimmerman RS. Health behavior theory and cumulative knowledge regarding health behaviors: are we moving in the right direction? *Health Educ Res*. 2005;20(3):275-290. [FREE Full text] [doi: [10.1093/her/cyg113](https://doi.org/10.1093/her/cyg113)] [Medline: [15632099](https://pubmed.ncbi.nlm.nih.gov/15632099/)]
50. Michie S, van Stralen MM, West R. The behaviour change wheel: a new method for characterising and designing behaviour change interventions. *Implement Sci*. 2011;6:42. [FREE Full text] [doi: [10.1186/1748-5908-6-42](https://doi.org/10.1186/1748-5908-6-42)] [Medline: [21513547](https://pubmed.ncbi.nlm.nih.gov/21513547/)]
51. Bartholomew LK, Parcel GS, Kok G. Intervention mapping: a process for developing theory- and evidence-based health education programs. *Health Educ Behav*. 1998;25(5):545-563. [doi: [10.1177/109019819802500502](https://doi.org/10.1177/109019819802500502)] [Medline: [9768376](https://pubmed.ncbi.nlm.nih.gov/9768376/)]
52. Renger R, Titcomb A. A three-step approach to teaching logic models. *Am J Eval*. 2016;23(4):493-503. [doi: [10.1177/109821400202300409](https://doi.org/10.1177/109821400202300409)]
53. Renger R, Hurley C. From theory to practice: lessons learned in the application of the ATM approach to developing logic models. *Eval Program Plann*. 2006;29(2):106-119. [doi: [10.1016/j.evalprogplan.2006.01.004](https://doi.org/10.1016/j.evalprogplan.2006.01.004)]
54. Martin F, Turner A, Bourne C, Batehup L. Development and qualitative evaluation of a self-management workshop for testicular cancer survivor-initiated follow-up. *Oncol Nurs Forum*. 2013;40(1):E14-E23. [doi: [10.1188/13.ONF.E14-E23](https://doi.org/10.1188/13.ONF.E14-E23)] [Medline: [23269777](https://pubmed.ncbi.nlm.nih.gov/23269777/)]
55. Martin F, Turner A, Wallace LM, Bradbury N. Conceptualisation of self-management intervention for people with early stage dementia. *Eur J Ageing*. 2013;10(2):75-87. [FREE Full text] [doi: [10.1007/s10433-012-0253-5](https://doi.org/10.1007/s10433-012-0253-5)] [Medline: [28804285](https://pubmed.ncbi.nlm.nih.gov/28804285/)]
56. Gale NK, Heath G, Cameron E, Rashid S, Redwood S. Using the framework method for the analysis of qualitative data in multi-disciplinary health research. *BMC Med Res Methodol*. 2013;13:117. [FREE Full text] [doi: [10.1186/1471-2288-13-117](https://doi.org/10.1186/1471-2288-13-117)] [Medline: [24047204](https://pubmed.ncbi.nlm.nih.gov/24047204/)]
57. Barry JA, Kuczmierczyk AR, Hardiman PJ. Anxiety and depression in polycystic ovary syndrome: a systematic review and meta-analysis. *Hum Reprod*. 2011;26(9):2442-2451. [FREE Full text] [doi: [10.1093/humrep/der197](https://doi.org/10.1093/humrep/der197)] [Medline: [21725075](https://pubmed.ncbi.nlm.nih.gov/21725075/)]
58. Bazarganipour F, Taghavi SA, Montazeri A, Ahmadi F, Chaman R, Khosravi A. The impact of polycystic ovary syndrome on the health-related quality of life: a systematic review and meta-analysis. *Iran J Reprod Med*. 2015;13(2):61-70. [FREE Full text] [Medline: [25999994](https://pubmed.ncbi.nlm.nih.gov/25999994/)]
59. Blay SL, Aguiar JVA, Passos IC. Polycystic ovary syndrome and mental disorders: a systematic review and exploratory meta-analysis. *Neuropsychiatr Dis Treat*. 2016;12:2895-2903. [FREE Full text] [doi: [10.2147/NDT.S91700](https://doi.org/10.2147/NDT.S91700)] [Medline: [27877043](https://pubmed.ncbi.nlm.nih.gov/27877043/)]
60. Brutocao C, Zaiem F, Alsawas M, Morrow AS, Murad MH, Javed A. Psychiatric disorders in women with polycystic ovary syndrome: a systematic review and meta-analysis. *Endocrine*. 2018;62(2):318-325. [doi: [10.1007/s12020-018-1692-3](https://doi.org/10.1007/s12020-018-1692-3)] [Medline: [30066285](https://pubmed.ncbi.nlm.nih.gov/30066285/)]
61. Conte F, Banting L, Teede HJ, Stepto NK. Mental health and physical activity in women with polycystic ovary syndrome: a brief review. *Sports Med*. 2015;45(4):497-504. [FREE Full text] [doi: [10.1007/s40279-014-0291-6](https://doi.org/10.1007/s40279-014-0291-6)] [Medline: [25430602](https://pubmed.ncbi.nlm.nih.gov/25430602/)]
62. Dokras A, Clifton S, Futterweit W, Wild R. Increased risk for abnormal depression scores in women with polycystic ovary syndrome: a systematic review and meta-analysis. *Obstet Gynecol*. 2011;117(1):145-152. [doi: [10.1097/AOG.0b013e318202b0a4](https://doi.org/10.1097/AOG.0b013e318202b0a4)] [Medline: [21173657](https://pubmed.ncbi.nlm.nih.gov/21173657/)]
63. Gibson-Helm M, Tassone EC, Teede HJ, Dokras A, Garad R. The needs of women and healthcare providers regarding polycystic ovary syndrome information, resources, and education: a systematic search and narrative review. *Semin Reprod Med*. 2018;36(1):35-41. [doi: [10.1055/s-0038-1668086](https://doi.org/10.1055/s-0038-1668086)] [Medline: [30189449](https://pubmed.ncbi.nlm.nih.gov/30189449/)]

64. Kaczmarek C, Haller DM, Yaron M. Health-related quality of life in adolescents and young adults with polycystic ovary syndrome: a systematic review. *J Pediatr Adolesc Gynecol*. 2016;29(6):551-557. [doi: [10.1016/j.jpag.2016.05.006](https://doi.org/10.1016/j.jpag.2016.05.006)] [Medline: [27262833](https://pubmed.ncbi.nlm.nih.gov/27262833/)]
65. Taghavi SA, Bazarganipour F, Montazeri A, Kazemnejad A, Chaman R, Khosravi A. Health-related quality of life in polycystic ovary syndrome patients: a systematic review. *Iran J Reprod Med*. 2015;13(8):473-482. [FREE Full text] [Medline: [26568749](https://pubmed.ncbi.nlm.nih.gov/26568749/)]
66. Dokras A, Clifton S, Futterweit W, Wild R. Increased prevalence of anxiety symptoms in women with polycystic ovary syndrome: systematic review and meta-analysis. *Fertil Steril*. 2012;97(1):225-230.e2. [FREE Full text] [doi: [10.1016/j.fertnstert.2011.10.022](https://doi.org/10.1016/j.fertnstert.2011.10.022)] [Medline: [22127370](https://pubmed.ncbi.nlm.nih.gov/22127370/)]
67. Thomson RL, Buckley JD, Brinkworth GD. Exercise for the treatment and management of overweight women with polycystic ovary syndrome: a review of the literature. *Obes Rev*. 2011;12(5):e202-e210. [FREE Full text] [doi: [10.1111/j.1467-789X.2010.00758.x](https://doi.org/10.1111/j.1467-789X.2010.00758.x)] [Medline: [20546140](https://pubmed.ncbi.nlm.nih.gov/20546140/)]
68. Veltman-Verhulst SM, Boivin J, Eijkemans M, Fauser BJCM. Emotional distress is a common risk in women with polycystic ovary syndrome: a systematic review and meta-analysis of 28 studies. *Hum Reprod Update*. 2012;18(6):638-651. [FREE Full text] [doi: [10.1093/humupd/dms029](https://doi.org/10.1093/humupd/dms029)] [Medline: [22824735](https://pubmed.ncbi.nlm.nih.gov/22824735/)]
69. Pearce G, Parke HL, Pinnock H, Epiphaniou E, Bourne CLA, Sheikh A, et al. The PRISMS taxonomy of self-management support: derivation of a novel taxonomy and initial testing of its utility. *J Health Serv Res Policy*. 2016;21(2):73-82. [FREE Full text] [doi: [10.1177/1355819615602725](https://doi.org/10.1177/1355819615602725)] [Medline: [26377727](https://pubmed.ncbi.nlm.nih.gov/26377727/)]
70. Ismayilova M, Yaya S. "I felt like she didn't take me seriously": a multi-methods study examining patient satisfaction and experiences with Polycystic Ovary Syndrome (PCOS) in Canada. *BMC Womens Health*. 2022;22(1):47. [FREE Full text] [doi: [10.1186/s12905-022-01630-3](https://doi.org/10.1186/s12905-022-01630-3)] [Medline: [35197027](https://pubmed.ncbi.nlm.nih.gov/35197027/)]
71. Ismayilova M, Yaya S. What can be done to improve Polycystic Ovary Syndrome (PCOS) healthcare? Insights from semi-structured interviews with women in Canada. *BMC Womens Health*. 2022;22(1):157. [FREE Full text] [doi: [10.1186/s12905-022-01734-w](https://doi.org/10.1186/s12905-022-01734-w)] [Medline: [35538531](https://pubmed.ncbi.nlm.nih.gov/35538531/)]
72. Avery JC, Braunack-Mayer AJ. The information needs of women diagnosed with polycystic ovarian syndrome--implications for treatment and health outcomes. *BMC Womens Health*. 2007;7:9. [FREE Full text] [doi: [10.1186/1472-6874-7-9](https://doi.org/10.1186/1472-6874-7-9)] [Medline: [17578583](https://pubmed.ncbi.nlm.nih.gov/17578583/)]
73. Douglas CC, Jones R, Green R, Brown K, Yount G, Williams R. University students with PCOS demonstrate limited nutrition knowledge. *Am J Health Educ*. 2021;52(2):80-91. [doi: [10.1080/19325037.2021.1877218](https://doi.org/10.1080/19325037.2021.1877218)]
74. Pramodh S. Exploration of lifestyle choices, reproductive health knowledge, and Polycystic Ovary Syndrome (PCOS) awareness among female Emirati University students. *Int J Womens Health*. 2020;12:927-938. [FREE Full text] [doi: [10.2147/IJWH.S272867](https://doi.org/10.2147/IJWH.S272867)] [Medline: [33149703](https://pubmed.ncbi.nlm.nih.gov/33149703/)]
75. Bazarganipour F, Taghavi SA, Allan H, Hosseini N. Facilitating and inhibiting factors related to treatment adherence in women with polycystic ovary syndrome: a qualitative study. *Int J Reprod Biomed*. 2017;15(9):553-560. [FREE Full text] [Medline: [29662963](https://pubmed.ncbi.nlm.nih.gov/29662963/)]
76. Holbrey S, Coulson NS. A qualitative investigation of the impact of peer to peer online support for women living with polycystic ovary syndrome. *BMC Womens Health*. 2013;13:51. [FREE Full text] [doi: [10.1186/1472-6874-13-51](https://doi.org/10.1186/1472-6874-13-51)] [Medline: [24341398](https://pubmed.ncbi.nlm.nih.gov/24341398/)]
77. Percy C, Murray S. The role of an online peer-to-peer health community in addressing psychosocial concerns and social support in polycystic ovary syndrome. *Int J Web Based Communities*. 2010;6(4):349. [doi: [10.1504/ijwbc.2010.035838](https://doi.org/10.1504/ijwbc.2010.035838)]
78. Percy CA, Gibbs T, Potter L, Boardman S. Nurse-led peer support group: experiences of women with polycystic ovary syndrome. *J Adv Nurs*. 2009;65(10):2046-2055. [doi: [10.1111/j.1365-2648.2009.05061.x](https://doi.org/10.1111/j.1365-2648.2009.05061.x)] [Medline: [19686401](https://pubmed.ncbi.nlm.nih.gov/19686401/)]
79. Mani H, Chudasama Y, Hadjiconstantinou M, Bodicoat DH, Edwardson C, Levy MJ, et al. Structured education programme for women with polycystic ovary syndrome: a randomised controlled trial. *Endocr Connect*. 2018;7(1):26-35. [FREE Full text] [doi: [10.1530/EC-17-0274](https://doi.org/10.1530/EC-17-0274)] [Medline: [29133383](https://pubmed.ncbi.nlm.nih.gov/29133383/)]
80. Saroja CSM, Chandrashekar SH. Polycystic ovaries: review of medical information on the internet for patients. *Arch Gynecol Obstet*. 2010;281(5):839-843. [doi: [10.1007/s00404-010-1378-4](https://doi.org/10.1007/s00404-010-1378-4)] [Medline: [20143080](https://pubmed.ncbi.nlm.nih.gov/20143080/)]
81. Mousiolis A, Michala L, Antsaklis A. Polycystic ovary syndrome: double click and right check. What do patients learn from the internet about PCOS? *Eur J Obstet Gynecol Reprod Biol*. 2012;163(1):43-46. [doi: [10.1016/j.ejogrb.2012.03.028](https://doi.org/10.1016/j.ejogrb.2012.03.028)] [Medline: [22512829](https://pubmed.ncbi.nlm.nih.gov/22512829/)]
82. Kaur I, Suri V, Rana SV, Singh A. Treatment pathways traversed by Polycystic Ovary Syndrome (PCOS) patients: a mixed-method study. *PLoS One*. 2021;16(8):e0255830. [FREE Full text] [doi: [10.1371/journal.pone.0255830](https://doi.org/10.1371/journal.pone.0255830)] [Medline: [34370764](https://pubmed.ncbi.nlm.nih.gov/34370764/)]
83. Copp T, Muscat DM, Hersch J, McCaffery KJ, Doust J, Dokras A, et al. The challenges with managing polycystic ovary syndrome: a qualitative study of women's and clinicians' experiences. *Patient Educ Couns*. 2022;105(3):719-725. [doi: [10.1016/j.pec.2021.05.038](https://doi.org/10.1016/j.pec.2021.05.038)] [Medline: [34099308](https://pubmed.ncbi.nlm.nih.gov/34099308/)]
84. Williams S, Sheffield D, Knibb RC. 'Everything's from the inside out with PCOS': exploring women's experiences of living with polycystic ovary syndrome and co-morbidities through Skype™ interviews. *Health Psychol Open*. 2015;2(2):2055102915603051. [FREE Full text] [doi: [10.1177/2055102915603051](https://doi.org/10.1177/2055102915603051)] [Medline: [28070371](https://pubmed.ncbi.nlm.nih.gov/28070371/)]

85. Sadhwani S. Living with grief: a phenomenological analysis of the lived experience of PCOS. *Eur Health Psychol.* 2016;18(Suppl):1018.
86. Boyle JA, Xu R, Gilbert E, Kuczynska-Burggraf M, Tan B, Teede H, et al. Ask PCOS: identifying need to inform evidence-based app development for polycystic ovary syndrome. *Semin Reprod Med.* 2018;36(1):59-65. [doi: [10.1055/s-0038-1667187](https://doi.org/10.1055/s-0038-1667187)] [Medline: [30189452](https://pubmed.ncbi.nlm.nih.gov/30189452/)]
87. Epton T, Currie S, Armitage CJ. Unique effects of setting goals on behavior change: systematic review and meta-analysis. *J Consult Clin Psychol.* 2017;85(12):1182-1198. [doi: [10.1037/ccp0000260](https://doi.org/10.1037/ccp0000260)] [Medline: [29189034](https://pubmed.ncbi.nlm.nih.gov/29189034/)]
88. Lenzen SA, Daniëls R, van Bokhoven MA, van der Weijden T, Beurskens A. Disentangling self-management goal setting and action planning: a scoping review. *PLoS One.* 2017;12(11):e0188822. [FREE Full text] [doi: [10.1371/journal.pone.0188822](https://doi.org/10.1371/journal.pone.0188822)] [Medline: [29176800](https://pubmed.ncbi.nlm.nih.gov/29176800/)]
89. Boeykens D, Boeckxstaens P, De Sutter A, Lahousse L, Pype P, De Vriendt P, et al. Goal-oriented care for patients with chronic conditions or multimorbidity in primary care: a scoping review and concept analysis. *PLoS One.* 2022;17(2):e0262843. [FREE Full text] [doi: [10.1371/journal.pone.0262843](https://doi.org/10.1371/journal.pone.0262843)] [Medline: [35120137](https://pubmed.ncbi.nlm.nih.gov/35120137/)]
90. Jeong YH, Healy LC, McEwan D. The application of goal setting theory to goal setting interventions in sport: a systematic review. *Int Rev Sport Exerc Psychol.* 2023;16(1):474-499. [FREE Full text] [doi: [10.1080/1750984x.2021.1901298](https://doi.org/10.1080/1750984x.2021.1901298)]
91. Damone AL, Joham AE, Loxton D, Earnest A, Teede HJ, Moran LJ. Depression, anxiety and perceived stress in women with and without PCOS: a community-based study. *Psychol Med.* 2019;49(9):1510-1520. [doi: [10.1017/S0033291718002076](https://doi.org/10.1017/S0033291718002076)] [Medline: [30131078](https://pubmed.ncbi.nlm.nih.gov/30131078/)]
92. Papalou O, Diamanti-Kandarakis E. The role of stress in PCOS. *Expert Rev Endocrinol Metab.* 2017;12(1):87-95. [doi: [10.1080/17446651.2017.1266250](https://doi.org/10.1080/17446651.2017.1266250)] [Medline: [30058880](https://pubmed.ncbi.nlm.nih.gov/30058880/)]
93. Basu BR, Chowdhury O, Saha SK. Possible link between stress-related factors and altered body composition in women with polycystic ovarian syndrome. *J Hum Reprod Sci.* 2018;11(1):10-18. [FREE Full text] [doi: [10.4103/jhrs.JHRS_78_17](https://doi.org/10.4103/jhrs.JHRS_78_17)] [Medline: [29681710](https://pubmed.ncbi.nlm.nih.gov/29681710/)]
94. Stefanaki C, Bacopoulou F, Livadas S, Kandaraki A, Karachalios A, Chrousos GP, et al. Impact of a mindfulness stress management program on stress, anxiety, depression and quality of life in women with polycystic ovary syndrome: a randomized controlled trial. *Stress.* 2015;18(1):57-66. [FREE Full text] [doi: [10.3109/10253890.2014.974030](https://doi.org/10.3109/10253890.2014.974030)] [Medline: [25287137](https://pubmed.ncbi.nlm.nih.gov/25287137/)]
95. Young CC, Monge M, Minami H, Rew L, Conroy H, Peretz C, et al. Outcomes of a mindfulness-based healthy lifestyle intervention for adolescents and young adults with polycystic ovary syndrome. *J Pediatr Adolesc Gynecol.* 2022;35(3):305-313. [FREE Full text] [doi: [10.1016/j.jpag.2021.10.016](https://doi.org/10.1016/j.jpag.2021.10.016)] [Medline: [34742935](https://pubmed.ncbi.nlm.nih.gov/34742935/)]
96. Brockmann AN, Ross KM. Bidirectional association between stress and physical activity in adults with overweight and obesity. *J Behav Med.* 2020;43(2):246-253. [FREE Full text] [doi: [10.1007/s10865-020-00145-2](https://doi.org/10.1007/s10865-020-00145-2)] [Medline: [32130566](https://pubmed.ncbi.nlm.nih.gov/32130566/)]
97. Burg MM, Schwartz JE, Kronish IM, Diaz KM, Alcantara C, Duer-Hefele J, et al. Does stress result in you exercising less? Or does exercising result in you being less stressed? Or is it both? Testing the bi-directional stress-exercise association at the group and person (N of 1) level. *Ann Behav Med.* 2017;51(6):799-809. [FREE Full text] [doi: [10.1007/s12160-017-9902-4](https://doi.org/10.1007/s12160-017-9902-4)] [Medline: [28290065](https://pubmed.ncbi.nlm.nih.gov/28290065/)]
98. Woodward A, Klonizakis M, Broom D. Exercise and polycystic ovary syndrome. In: *Advances in Experimental Medicine and Biology.* Singapore: Springer; 2020;123-136.
99. Patten RK, Pascoe MC, Moreno-Asso A, Boyle RA, Stepto NK, Parker AG. Effectiveness of exercise interventions on mental health and health-related quality of life in women with polycystic ovary syndrome: a systematic review. *BMC Public Health.* 2021;21(1):2310. [FREE Full text] [doi: [10.1186/s12889-021-12280-9](https://doi.org/10.1186/s12889-021-12280-9)] [Medline: [34930180](https://pubmed.ncbi.nlm.nih.gov/34930180/)]
100. Abdollahi L, Mirghafourvand M, Babapour JK, Mohammadi M. Effectiveness of Cognitive-Behavioral Therapy (CBT) in improving the quality of life and psychological fatigue in women with polycystic ovarian syndrome: a randomized controlled clinical trial. *J Psychosom Obstet Gynaecol.* 2019;40(4):283-293. [doi: [10.1080/0167482X.2018.1502265](https://doi.org/10.1080/0167482X.2018.1502265)] [Medline: [30175648](https://pubmed.ncbi.nlm.nih.gov/30175648/)]
101. Cooney L, Milman LW, Sammel M, Allison K, Epperson C, Dokras A. Cognitive behavioral therapy improves weight loss and quality of life in women with Polycystic Ovary Syndrome (PCOS). *Fertil Steril.* 2016;106(3):e252-e253. [FREE Full text] [doi: [10.1016/j.fertnstert.2016.07.729](https://doi.org/10.1016/j.fertnstert.2016.07.729)]
102. Jiskoot G, Benneheij SH, Beerthuizen A, de Niet JE, de Klerk C, Timman R, et al. A three-component cognitive behavioural lifestyle program for preconceptional weight-loss in women with Polycystic Ovary Syndrome (PCOS): a protocol for a randomized controlled trial. *Reprod Health.* 2017;14(1):34. [FREE Full text] [doi: [10.1186/s12978-017-0295-4](https://doi.org/10.1186/s12978-017-0295-4)] [Medline: [28264692](https://pubmed.ncbi.nlm.nih.gov/28264692/)]
103. Jiskoot G, de Loos AD, Beerthuizen A, Timman R, Busschbach J, Laven J. Long-term effects of a three-component lifestyle intervention on emotional well-being in women with Polycystic Ovary Syndrome (PCOS): a secondary analysis of a randomized controlled trial. *PLoS One.* 2020;15(6):e0233876. [FREE Full text] [doi: [10.1371/journal.pone.0233876](https://doi.org/10.1371/journal.pone.0233876)] [Medline: [32479544](https://pubmed.ncbi.nlm.nih.gov/32479544/)]
104. Biber DD, Ellis R. The effect of self-compassion on the self-regulation of health behaviors: a systematic review. *J Health Psychol.* 2019;24(14):2060-2071. [doi: [10.1177/1359105317713361](https://doi.org/10.1177/1359105317713361)] [Medline: [28810473](https://pubmed.ncbi.nlm.nih.gov/28810473/)]

105. Braun TD, Park CL, Gorin A. Self-compassion, body image, and disordered eating: a review of the literature. *Body Image*. 2016;17:117-131. [doi: [10.1016/j.bodyim.2016.03.003](https://doi.org/10.1016/j.bodyim.2016.03.003)] [Medline: [27038782](https://pubmed.ncbi.nlm.nih.gov/27038782/)]
106. Rahimi-Ardabili H, Reynolds R, Vartanian LR, McLeod LVD, Zwar N. A systematic review of the efficacy of interventions that aim to increase self-compassion on nutrition habits, eating behaviours, body weight and body image. *Mindfulness*. 2017;9(2):388-400. [doi: [10.1007/s12671-017-0804-0](https://doi.org/10.1007/s12671-017-0804-0)]
107. Turk F, Waller G. Is self-compassion relevant to the pathology and treatment of eating and body image concerns? A systematic review and meta-analysis. *Clin Psychol Rev*. 2020;79:101856. [doi: [10.1016/j.cpr.2020.101856](https://doi.org/10.1016/j.cpr.2020.101856)] [Medline: [32438284](https://pubmed.ncbi.nlm.nih.gov/32438284/)]
108. Austin J, Drossaert CHC, Schroevers MJ, Sanderman R, Kirby JN, Bohlmeijer ET. Compassion-based interventions for people with long-term physical conditions: a mixed methods systematic review. *Psychol Health*. 2021;36(1):16-42. [FREE Full text] [doi: [10.1080/08870446.2019.1699090](https://doi.org/10.1080/08870446.2019.1699090)] [Medline: [32116052](https://pubmed.ncbi.nlm.nih.gov/32116052/)]
109. Carter A, Gilbert P, Kirby JN. A systematic review of compassion-based interventions for individuals struggling with body weight shame. *Psychol Health*. 2023;38(1):94-124. [doi: [10.1080/08870446.2021.1955118](https://doi.org/10.1080/08870446.2021.1955118)] [Medline: [34694950](https://pubmed.ncbi.nlm.nih.gov/34694950/)]
110. Kılıç A, Hudson J, McCracken LM, Ruparelia R, Fawson S, Hughes LD. A systematic review of the effectiveness of self-compassion-related interventions for individuals with chronic physical health conditions. *Behav Ther*. 2021;52(3):607-625. [doi: [10.1016/j.beth.2020.08.001](https://doi.org/10.1016/j.beth.2020.08.001)] [Medline: [33990237](https://pubmed.ncbi.nlm.nih.gov/33990237/)]
111. Wakelin KE, Perman G, Simonds LM. Effectiveness of self-compassion-related interventions for reducing self-criticism: a systematic review and meta-analysis. *Clin Psychol Psychother*. 2022;29(1):1-25. [FREE Full text] [doi: [10.1002/cpp.2586](https://doi.org/10.1002/cpp.2586)] [Medline: [33749936](https://pubmed.ncbi.nlm.nih.gov/33749936/)]
112. Taghavi SA, Aramesh S, Azizi-Kutenaee M, Allan H, Safarzadeh T, Taheri M, et al. The influence of infertility on sexual and marital satisfaction in Iranian women with polycystic ovary syndrome: a case-control study. *Middle East Fertil Soc J*. 2021;26(1):2. [FREE Full text] [doi: [10.1186/s43043-020-00047-y](https://doi.org/10.1186/s43043-020-00047-y)]
113. Thannickal A, Brutocao C, Alsawas M, Morrow A, Zaiem F, Murad MH, et al. Eating, sleeping and sexual function disorders in women with Polycystic Ovary Syndrome (PCOS): a systematic review and meta-analysis. *Clin Endocrinol (Oxf)*. 2020;92(4):338-349. [doi: [10.1111/cen.14153](https://doi.org/10.1111/cen.14153)] [Medline: [31917860](https://pubmed.ncbi.nlm.nih.gov/31917860/)]
114. Fliegner M, Richter-Appelt H, Krupp K, Brunner F. Sexual function and socio-sexual difficulties in women with Polycystic Ovary Syndrome (PCOS). *Geburtshilfe Frauenheilkd*. 2019;79(5):498-509. [FREE Full text] [doi: [10.1055/a-0828-7901](https://doi.org/10.1055/a-0828-7901)] [Medline: [31148850](https://pubmed.ncbi.nlm.nih.gov/31148850/)]
115. Loh HH, Yee A, Loh HS, Kanagasundram S, Francis B, Lim LL. Sexual dysfunction in polycystic ovary syndrome: a systematic review and meta-analysis. *Hormones (Athens)*. 2020;19(3):413-423. [doi: [10.1007/s42000-020-00210-0](https://doi.org/10.1007/s42000-020-00210-0)] [Medline: [32462512](https://pubmed.ncbi.nlm.nih.gov/32462512/)]
116. Mantzou D, Stamou MI, Armeni AK, Roupas ND, Assimakopoulos K, Adonakis G, et al. Impaired sexual function in young women with PCOS: the detrimental effect of anovulation. *J Sex Med*. 2021;18(11):1872-1879. [FREE Full text] [doi: [10.1016/j.jsxm.2021.09.004](https://doi.org/10.1016/j.jsxm.2021.09.004)] [Medline: [34610894](https://pubmed.ncbi.nlm.nih.gov/34610894/)]
117. Javed H, Niazi S, Adil A, Yousaf A, Khan A, Ghayas S. Body image concern as mediator between obesity and sexual satisfaction: a comparative study of married women with and without polycystic ovarian syndrome. *Rawal Med J*. 2022;47(2):400-402.
118. Naumova I, Castelo-Branco C, Casals G. Psychological issues and sexual function in women with different infertility causes: focus on polycystic ovary syndrome. *Reprod Sci*. 2021;28(10):2830-2838. [doi: [10.1007/s43032-021-00546-x](https://doi.org/10.1007/s43032-021-00546-x)] [Medline: [33763818](https://pubmed.ncbi.nlm.nih.gov/33763818/)]
119. Nappi RE, Tiranini L. Polycystic ovary syndrome and sexuality. *Gynecol Endocrinol*. 2022;38(7):535-536. [FREE Full text] [doi: [10.1080/09513590.2022.2089109](https://doi.org/10.1080/09513590.2022.2089109)] [Medline: [35723583](https://pubmed.ncbi.nlm.nih.gov/35723583/)]
120. Ee C, Smith C, Moran L, MacMillan F, Costello M, Baylock B, et al. "The whole package deal": experiences of overweight/obese women living with polycystic ovary syndrome. *BMC Womens Health*. 2020;20(1):221. [FREE Full text] [doi: [10.1186/s12905-020-01090-7](https://doi.org/10.1186/s12905-020-01090-7)] [Medline: [33008386](https://pubmed.ncbi.nlm.nih.gov/33008386/)]
121. Pfister G, Rømer K. "It's not very feminine to have a mustache": experiences of Danish women with polycystic ovary syndrome. *Health Care Women Int*. 2017;38(2):167-186. [doi: [10.1080/07399332.2016.1236108](https://doi.org/10.1080/07399332.2016.1236108)] [Medline: [27630044](https://pubmed.ncbi.nlm.nih.gov/27630044/)]
122. Thorpe C, Arbeau KJ, Budlong B. 'I drew the parts of my body in proportion to how much PCOS ruined them': experiences of polycystic ovary syndrome through drawings. *Health Psychol Open*. 2019;6(2):1-8. [FREE Full text] [doi: [10.1177/2055102919896238](https://doi.org/10.1177/2055102919896238)] [Medline: [31903221](https://pubmed.ncbi.nlm.nih.gov/31903221/)]
123. Yin MXC, Leng LL, Liang Z, Chen XY, Chan CHY, Chan CLW. Objectification and ambiguity of body image in women with polycystic ovary syndrome: a mixed-method study. *J Affect Disord*. 2022;310:296-303. [doi: [10.1016/j.jad.2022.05.028](https://doi.org/10.1016/j.jad.2022.05.028)] [Medline: [35561883](https://pubmed.ncbi.nlm.nih.gov/35561883/)]
124. Rafique S, Ilyas U. Psychosocial correlates of young females suffering from Polycystic Ovarian Syndrome (PCOS). *Pak Armed Forces Med J*. 2022;72(1):331-333. [FREE Full text] [doi: [10.51253/pafmj.v72i1.6225](https://doi.org/10.51253/pafmj.v72i1.6225)]
125. Naz MSG, Tehrani FR, Ozgoli G. Polycystic ovary syndrome in adolescents: a qualitative study. *Psychol Res Behav Manag*. 2019;12:715-723. [FREE Full text] [doi: [10.2147/PRBM.S207727](https://doi.org/10.2147/PRBM.S207727)] [Medline: [31686927](https://pubmed.ncbi.nlm.nih.gov/31686927/)]
126. Taghavi SA, Bazarganipour F, Hugh-Jones S, Hosseini N. Health-related quality of life in Iranian women with polycystic ovary syndrome: a qualitative study. *BMC Womens Health*. 2015;15:111. [FREE Full text] [doi: [10.1186/s12905-015-0272-4](https://doi.org/10.1186/s12905-015-0272-4)]

127. Amiri FN, Tehrani FR, Simbar M, Montazeri A, Thamtan RAM. The experience of women affected by polycystic ovary syndrome: a qualitative study from Iran. *Int J Endocrinol Metab*. 2014;12(2):e13612. [FREE Full text] [doi: [10.5812/ijem.13612](https://doi.org/10.5812/ijem.13612)] [Medline: [24829583](https://pubmed.ncbi.nlm.nih.gov/24829583/)]
128. Legault L, Sago A. When body positivity falls flat: divergent effects of body acceptance messages that support vs. undermine basic psychological needs. *Body Image*. 2022;41:225-238. [doi: [10.1016/j.bodyim.2022.02.013](https://doi.org/10.1016/j.bodyim.2022.02.013)] [Medline: [35305477](https://pubmed.ncbi.nlm.nih.gov/35305477/)]
129. Ulian MD, Aburad L, da Silva Oliveira MS, Poppe ACM, Sabatini F, Perez I, et al. Effects of health at every size® interventions on health-related outcomes of people with overweight and obesity: a systematic review. *Obes Rev*. 2018;19(12):1659-1666. [doi: [10.1111/obr.12749](https://doi.org/10.1111/obr.12749)] [Medline: [30261553](https://pubmed.ncbi.nlm.nih.gov/30261553/)]
130. Simonsmeier BA, Andronie M, Buecker S, Frank C. The effects of imagery interventions in sports: a meta-analysis. *Int Rev Sport Exerc Psychol*. 2020;14(1):186-207. [doi: [10.1080/1750984x.2020.1780627](https://doi.org/10.1080/1750984x.2020.1780627)]
131. Parham SC, Kavanagh DJ, Shimada M, May J, Andrade J. Qualitative analysis of feedback on functional imagery training: a novel motivational intervention for type 2 diabetes. *Psychol Health*. 2018;33(3):416-429. [doi: [10.1080/08870446.2017.1360493](https://doi.org/10.1080/08870446.2017.1360493)] [Medline: [28786698](https://pubmed.ncbi.nlm.nih.gov/28786698/)]
132. Solbrig L, Jones R, Kavanagh D, May J, Parkin T, Andrade J. People trying to lose weight dislike calorie counting apps and want motivational support to help them achieve their goals. *Internet Interv*. 2017;7:23-31. [FREE Full text] [doi: [10.1016/j.invent.2016.12.003](https://doi.org/10.1016/j.invent.2016.12.003)] [Medline: [28286739](https://pubmed.ncbi.nlm.nih.gov/28286739/)]
133. Blackwell SE. Mental imagery: from basic research to clinical practice. *J Psychother Integr*. 2019;29(3):235-247. [doi: [10.1037/int0000108](https://doi.org/10.1037/int0000108)]
134. Pile V, Williamson G, Saunders A, Holmes EA, Lau JYF. Harnessing emotional mental imagery to reduce anxiety and depression in young people: an integrative review of progress and promise. *Lancet Psychiatry*. 2021;8(9):836-852. [doi: [10.1016/S2215-0366\(21\)00195-4](https://doi.org/10.1016/S2215-0366(21)00195-4)] [Medline: [34419188](https://pubmed.ncbi.nlm.nih.gov/34419188/)]
135. Ji JL, Holmes EA, Blackwell SE. Seeing light at the end of the tunnel: positive prospective mental imagery and optimism in depression. *Psychiatry Res*. 2017;247:155-162. [FREE Full text] [doi: [10.1016/j.psychres.2016.11.025](https://doi.org/10.1016/j.psychres.2016.11.025)] [Medline: [27907825](https://pubmed.ncbi.nlm.nih.gov/27907825/)]
136. Carr A, Cullen K, Keeney C, Canning C, Mooney O, Chinseallaigh E, et al. Effectiveness of positive psychology interventions: a systematic review and meta-analysis. *J Posit Psychol*. 2020;16(6):749-769. [doi: [10.1080/17439760.2020.1818807](https://doi.org/10.1080/17439760.2020.1818807)]
137. McTiernan K, Gullon-Scott F, Dudley R. Do positive psychology interventions impact on the subjective wellbeing and depression of clients? A systematic methodological review. *J Contemp Psychother*. 2021;52(1):1-13. [FREE Full text] [doi: [10.1007/s10879-021-09522-7](https://doi.org/10.1007/s10879-021-09522-7)]
138. Moskowitz JT, Cheung EO, Freedman M, Fernando C, Zhang MW, Huffman JC, et al. Measuring positive emotion outcomes in positive psychology interventions: a literature review. *Emot Rev*. 2020;13(1):60-73. [FREE Full text] [doi: [10.1177/1754073920950811](https://doi.org/10.1177/1754073920950811)]
139. Otusanya AD. "If you never came in and saw me, you would probably be dead": exploring intercultural communication and health communication issues surrounding PCOS. ProQuest Dissertations Publishing. 2020. URL: <https://www.proquest.com/openview/06b95b7e2f897452004ef1b83f664b40/1?pq-origsite=gscholar&cbl=18750&diss=y> [accessed 2024-01-31]
140. Chopra S, Zehring R, Shanmugam TA, Choe EK. Living with uncertainty and stigma: self-experimentation and support-seeking around polycystic ovary syndrome. 2021. Presented at: CHI '21: CHI Conference on Human Factors in Computing Systems; May 8-13, 2021, 2021; Yokohama, Japan. [doi: [10.1145/3411764.3445706](https://doi.org/10.1145/3411764.3445706)]
141. Sharma S, Mishra AJ. Tabooed disease in alienated bodies: a study of women suffering from Polycystic Ovary Syndrome (PCOS). *Clin Epidemiology Glob Health*. 2018;6(3):130-136. [FREE Full text] [doi: [10.1016/j.cegh.2017.09.001](https://doi.org/10.1016/j.cegh.2017.09.001)]
142. Ramesh R, Dinesh S. Psychosocial effects of PCOS on reproductive-age women; a preliminary exploratory study based in Kerala. *Malays J Public Health Med*. 2020;20(Special 1):305-310. [FREE Full text] [doi: [10.37268/mjphm/vol.20/no.special1/art.735](https://doi.org/10.37268/mjphm/vol.20/no.special1/art.735)]
143. Wright PJ, Dawson RM, Corbett CF. Social construction of biopsychosocial and medical experiences of women with polycystic ovary syndrome. *J Adv Nurs*. 2020;76(7):1728-1736. [doi: [10.1111/jan.14371](https://doi.org/10.1111/jan.14371)] [Medline: [32215949](https://pubmed.ncbi.nlm.nih.gov/32215949/)]
144. Soucie K, Samardzic T, Schramer K, Ly C, Katzman R. The diagnostic experiences of women with Polycystic Ovary Syndrome (PCOS) in Ontario, Canada. *Qual Health Res*. 2021;31(3):523-534. [doi: [10.1177/1049732320971235](https://doi.org/10.1177/1049732320971235)] [Medline: [33213256](https://pubmed.ncbi.nlm.nih.gov/33213256/)]
145. Lin AW, Bergomi EJ, Dollahite JS, Sobal J, Hoeger KM, Lujan ME. Trust in physicians and medical experience beliefs differ between women with and without polycystic ovary syndrome. *J Endocr Soc*. 2018;2(9):1001-1009. [FREE Full text] [doi: [10.1210/js.2018-00181](https://doi.org/10.1210/js.2018-00181)] [Medline: [30140785](https://pubmed.ncbi.nlm.nih.gov/30140785/)]
146. Tomlinson J, Pinkney J, Adams L, Stenhouse E, Bendall A, Corrigan O, et al. The diagnosis and lived experience of polycystic ovary syndrome: a qualitative study. *J Adv Nurs*. 2017;73(10):2318-2326. [doi: [10.1111/jan.13300](https://doi.org/10.1111/jan.13300)] [Medline: [28329428](https://pubmed.ncbi.nlm.nih.gov/28329428/)]
147. Lim S, Wright B, Savaglio M, Goodwin D, Pirotta S, Moran L. An analysis on the implementation of the evidence-based PCOS lifestyle guideline: recommendations from women with PCOS. *Semin Reprod Med*. 2021;39(3-04):153-160. [doi: [10.1055/s-0041-1735575](https://doi.org/10.1055/s-0041-1735575)] [Medline: [34461671](https://pubmed.ncbi.nlm.nih.gov/34461671/)]

148. Chhour I, Blackshaw L, Moran LJ, Boyle JA, Robinson T, Lim SS. Barriers and facilitators to the implementation of lifestyle management in polycystic ovary syndrome: endocrinologists' and obstetricians and gynaecologists' perspectives. *Patient Educ Couns*. 2022;105(7):2292-2298. [doi: [10.1016/j.pec.2021.12.013](https://doi.org/10.1016/j.pec.2021.12.013)] [Medline: [34980547](https://pubmed.ncbi.nlm.nih.gov/34980547/)]
149. Dunn P, Conard S. Improving health literacy in patients with chronic conditions: a call to action. *Int J Cardiol*. 2018;273:249-251. [doi: [10.1016/j.ijcard.2018.08.090](https://doi.org/10.1016/j.ijcard.2018.08.090)] [Medline: [30193793](https://pubmed.ncbi.nlm.nih.gov/30193793/)]
150. Hadjiconstantinou M, Mani H, Patel N, Levy M, Davies M, Khunti K, et al. Understanding and supporting women with polycystic ovary syndrome: a qualitative study in an ethnically diverse UK sample. *Endocr Connect*. 2017;6(5):323-330. [FREE Full text] [doi: [10.1530/EC-17-0053](https://doi.org/10.1530/EC-17-0053)] [Medline: [28515051](https://pubmed.ncbi.nlm.nih.gov/28515051/)]
151. Yalom ID, Leszcz M. *Theory and Practice of Group Psychotherapy*, 5th Edition. New York. Basic Books; 2005.
152. Avery J, Ottey S, Morman R, Cree-Green M, Gibson-Helm M. Polycystic ovary syndrome support groups and their role in awareness, advocacy and peer support: a systematic search and narrative review. *Curr Opin Endocr Metab Res*. 2020;12:98-104. [doi: [10.1016/j.coemr.2020.04.008](https://doi.org/10.1016/j.coemr.2020.04.008)]
153. Ranasinghe BA, Balasuriya A, Wijeyaratne CN, Fernando N. The impact of peer-led support groups on health-related quality of life, coping skills and depressive symptomatology for women with PCOS. *Psychol Health Med*. 2023;28(3):564-573. [doi: [10.1080/13548506.2021.2019805](https://doi.org/10.1080/13548506.2021.2019805)] [Medline: [34931908](https://pubmed.ncbi.nlm.nih.gov/34931908/)]
154. Roessler KK, Glintborg D, Ravn P, Birkebaek C, Andersen M. Supportive relationships--psychological effects of group counselling in women with Polycystic Ovary Syndrome (PCOS). *Commun Med*. 2012;9(2):125-131. [doi: [10.1558/cam.v9i2.125](https://doi.org/10.1558/cam.v9i2.125)] [Medline: [24498697](https://pubmed.ncbi.nlm.nih.gov/24498697/)]
155. Delisle VC, Gumuchian ST, Kloda LA, Boruff J, El-Baalbaki G, Körner A, et al. Effect of support group peer facilitator training programmes on peer facilitator and support group member outcomes: a systematic review. *BMJ Open*. 2016;6(11):e013325. [FREE Full text] [doi: [10.1136/bmjopen-2016-013325](https://doi.org/10.1136/bmjopen-2016-013325)] [Medline: [27856483](https://pubmed.ncbi.nlm.nih.gov/27856483/)]
156. Ramchand R, Ahluwalia SC, Xenakis L, Apaydin E, Raaen L, Grimm G. A systematic review of peer-supported interventions for health promotion and disease prevention. *Prev Med*. 2017;101:156-170. [doi: [10.1016/j.ypmed.2017.06.008](https://doi.org/10.1016/j.ypmed.2017.06.008)] [Medline: [28601621](https://pubmed.ncbi.nlm.nih.gov/28601621/)]
157. Satinsky E, Crepaz-Keay D, Kousoulis A. Making peer-focused self-management programmes work in public mental health. *J Ment Health Train Educ Pract*. 2018;13(5):257-263. [doi: [10.1108/jmhtep-08-2017-0052](https://doi.org/10.1108/jmhtep-08-2017-0052)]
158. PCOS and endometriosis to be debated in Parliament. Verity. 2018. URL: <https://www.verity-pcos.org.uk/parliamentarydebate.html> [accessed 2024-01-31]
159. Schlieter H, Marsch LA, Whitehouse D, Otto L, Londral AR, Teepe GW, et al. Scale-up of digital innovations in health care: expert commentary on enablers and barriers. *J Med Internet Res*. 2022;24(3):e24582. [FREE Full text] [doi: [10.2196/24582](https://doi.org/10.2196/24582)] [Medline: [35275065](https://pubmed.ncbi.nlm.nih.gov/35275065/)]
160. Hope for the Community—Community Interest Company. URL: <https://www.h4c.org.uk/> [accessed 2024-01-31]
161. Teede H, Tay CT, Laven J, Dokras A, Moran L, Piltonen T, et al. International evidence-based guideline for the assessment and management of polycystic ovary syndrome. Monash University. 2023. URL: https://www.monash.edu/data/assets/pdf_file/0003/3379521/Evidence-Based-Guidelines-2023.pdf [accessed 2024-01-31]
162. Gupta S, Mandil M, Das S, Ahirrao S, Sorathia K. SheHealthy: a serious game approach towards evicting PCOS amongst adolescent girls. 2015 Presented at: IndiaHCI '15: Proceedings of the 7th Indian Conference on Human-Computer Interaction; December 17-19, 2015, 2015;129-132; Guwahati, India. [doi: [10.1145/2835966.2836283](https://doi.org/10.1145/2835966.2836283)]
163. Karjula S, Morin-Papunen L, Franks S, Auvinen J, Järvelin MR, Tapanainen JS, et al. Population-based data at ages 31 and 46 show decreased HRQoL and life satisfaction in women with PCOS symptoms. *J Clin Endocrinol Metab*. 2020;105(6):1814-1826. [FREE Full text] [doi: [10.1210/clinem/dgz256](https://doi.org/10.1210/clinem/dgz256)] [Medline: [31970392](https://pubmed.ncbi.nlm.nih.gov/31970392/)]
164. Karjula S, Morin-Papunen L, Auvinen J, Ruokonen A, Puukka K, Franks S, et al. Psychological distress is more prevalent in fertile age and premenopausal women with PCOS symptoms: 15-year follow-up. *J Clin Endocrinol Metab*. 2017;102(6):1861-1869. [FREE Full text] [doi: [10.1210/jc.2016-3863](https://doi.org/10.1210/jc.2016-3863)] [Medline: [28323926](https://pubmed.ncbi.nlm.nih.gov/28323926/)]
165. Forslund M, Landin-Wilhelmsen K, Krantz E, Trimpou P, Schmidt J, Brännström M, et al. Health-related quality of life in perimenopausal women with PCOS. *Clin Exp Obstet Gynecol*. 2022;49(2):52. [FREE Full text] [doi: [10.31083/j.ceog4902052](https://doi.org/10.31083/j.ceog4902052)]

Abbreviations

- ATM:** antecedent target measure
- CBT:** cognitive behavioral therapy
- H4C:** Hope for the Community
- MRC:** Medical Research Council
- NHS:** National Health Service
- PCOS:** polycystic ovary syndrome
- PRISMS:** Practical Reviews in Self-Management Support

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