

Development of a question prompt list for women with polycystic ovary syndrome

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Objective: To develop a question prompt list (QPL) for women with polycystic ovary syndrome (PCOS) and explore its acceptability and feasibility.

Design: Nationwide online survey, interviews, and clinical pilot test.

Setting: Australia.

Patient(s): Two-hundred and forty-nine women online, 18 women in interviews, and 20 women in clinics.

Intervention(s): A QPL for PCOS.

Main Outcome Measure(s): From survey, women's likeliness to use a QPL and priority topics; from interview, QPL user-friendliness and associated feelings; from pilot, women's QPL use, perceived helpfulness, and intended future use.

Result(s): Evidence-based guidelines and multidisciplinary experts informed the QPL development. Of 249 survey respondents, 66.7% to 68.7% reported difficulty communicating with health care providers about mood, weight management, and how PCOS affects daily life, and 85.8% indicated they were very likely to use a PCOS QPL. Women were interviewed to explore acceptability; the semistructured interviews (n = 18) revealed that the devised QPL was easy to understand, user-friendly, and encouraged information seeking and targeted question asking. The refined QPL was pilot-tested in a clinic setting to explore feasibility between 2016 and 2017: 60.0% of women asked 1 to 2 questions from the QPL, 20.0% asked several questions, and 10.0% reported the QPL helped them generate their own questions. Women agreed the QPL was helpful (95.0%) and that they would use the QPL again (90.0%).

Conclusion(s): The PCOS QPL is acceptable and feasible, and may assist women in information seeking and targeted question asking. (Fertil Steril® 2018; ■:■–■. ©2018 by American Society for Reproductive Medicine.)

Key Words: Information seeking behavior, patient participation, polycystic ovary syndrome, question prompt list

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Polycystic ovary syndrome (PCOS) is the most common endocrine disorder affecting reproductive-age women (1). The implications of PCOS are wide-ranging and have profound effects on women's health. Regarded as a leading cause of anovulatory infertility (2), PCOS is

also associated with an increased risk of cardiovascular risk factors (3, 4), type 2 diabetes mellitus (5), anxiety, depression (6), and reduced quality of life (7). Excess weight is commonly implicated in PCOS and exacerbates both reproductive (8) and metabolic (9) features of the condition, although

these features can be significantly improved by moderate intensity physical activity and dietary modifications (10–12). Evidence-based guidelines for PCOS recommend that all women engage in lifestyle management and routine screening of risk factors (13).

Despite these recommendations, inadequate information provision about lifestyle management and long-term implications is a major source of dissatisfaction for women at the time of PCOS diagnosis (14). Women specifically report concerns about irregular menstrual cycles, infertility, weight, and hirsutism (14, 15). It is important to address women's information needs as the perception of receiving better

Received February 9, 2018; revised April 2, 2018; accepted April 17, 2018.

N.N.K. has nothing to disclose. A.V. has nothing to disclose. J.A.B. has nothing to disclose. M.B. has nothing to disclose. M.P. has nothing to disclose. H.T. has nothing to disclose. M.G.-H. has nothing to disclose.

Supported by project grants from the National Health and Medical Research Council and the Centre for Research Excellence in PCOS. J.A. Boyle, H. Teede, and M. Gibson-Helm are National Health and Medical Research Council Fellows. Copyright of the developed tool will remain with Monash University; however, no patent for the tool is planned, pending, or issued.

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Fertility and Sterility® Vol. ■, No. ■, ■ 2018 0015-0282/\$36.00

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<https://doi.org/10.1016/j.fertnstert.2018.04.028>

information about PCOS is associated with higher quality of life scores (16), suggesting a need to facilitate discussion about women's individual concerns during health care consultations.

A question prompt list (QPL) is a structured list of questions used by patients and/or their caregivers during medical consultations, designed to empower patients and optimize patient-centered care (17). Question prompt lists have been widely investigated in the settings of cancer (18–23), palliative care (24, 25), chronic conditions including attention deficit/hyperactivity disorder (26), and chronic obstructive pulmonary disease (27). They have been found to assist patients and caregivers to put their concerns into words (28), discuss difficult or sensitive issues (24), and ask more targeted questions (20, 22, 29). Studies also report that health care providers (28, 30) perceive that QPLs help people to discuss important issues. In this context, we aimed to develop a QPL for PCOS and explore its acceptability and feasibility.

MATERIALS AND METHODS

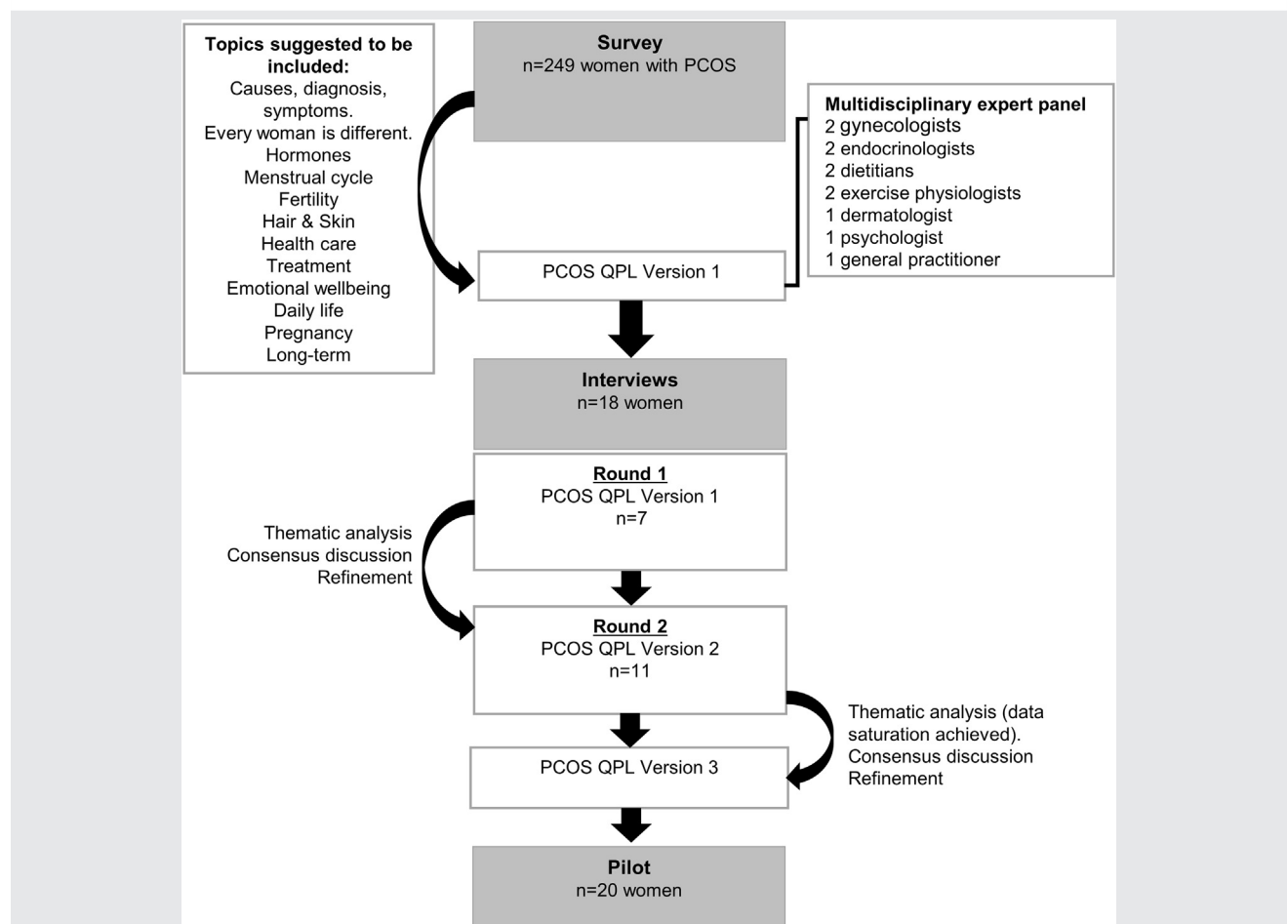
Study Design, Setting, and Participants

This study was conducted in Australia during 2016 and 2017 using consecutive phases (Fig. 1). Women were eligible to participate if they were at least 18 years of age, resided in Australia, and reported a previous medical diagnosis of PCOS. Informed consent was obtained from each participant. This study was approved by the Monash Health Human Research Ethics Committee (project 07070C).

Phase 1: Survey to Inform QPL Design

To assess the need for a QPL and to inform potential content, an online questionnaire was devised by a multidisciplinary team (A.V., J.A.B., M.B., H.T., and M.G.H.) with clinical and research expertise in PCOS and in survey research. The main outcome measures were how likely women would be to use a QPL and what priority topics to include. The questionnaire also enquired about demographics, aspects of PCOS

FIGURE 1



Development of the polycystic ovary syndrome (PCOS) question prompt list (QPL): study design including survey, interview and pilot phases. A survey of $n = 249$ women with PCOS and feedback from a multidisciplinary expert panel informed the content of the PCOS QPL Version 1. Interviews with women ($n = 18$) contributed to the iterative refinement of the QPL, producing QPL Version 2 and ultimately PCOS QPL Version 3. PCOS QPL Version 3 was pilot-tested in a clinic setting with $n = 20$ women with PCOS.

Khan. PCOS question prompt list. *Fertil Steril* 2018.

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