



# Polycystic Ovary Syndrome in Teens

## Development and Evaluation of an Informational Guidebook

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### Purpose and Objectives

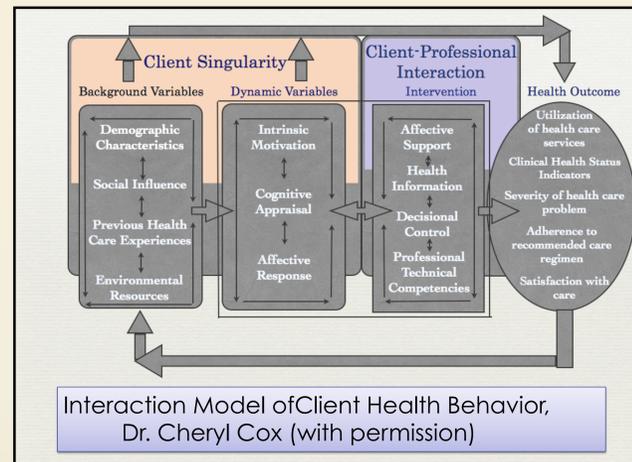
#### Purpose

- Develop a simple guidebook as handout for practitioners who diagnose and treat teens with PCOS
- Determine effectiveness of the guidebook

#### Objectives

- Make a simple but comprehensive guidebook to include physical, emotional, and social aspects of PCOS, as well as learning needs.
- Have young women with Polycystic Ovary Syndrome evaluate guidebook
  - ✓ Design
  - ✓ Content
  - ✓ Acceptance of this modality as a learning tool
- Revise Guidebook according to feedback
- Publish and disseminate to providers

### Model and Conceptual Framework



#### Critical Components

- Comprehensive interactive process involving client variables and client-professional interaction
- Bi-directional, ongoing process critical to relationship-building with teens having long-term disorder
- Client singularity concept, allowing for individualized approach to each teen.
- Essential elements of interactions with teens with chronic medical disorders:
  - ✓ Health information
  - ✓ Affective support
  - ✓ Decisional control rendered to clients
  - ✓ Technical competence by professionals

### Evidence and Background

#### Polycystic Ovary Syndrome

- PCOS affects 6-10% of all women, including teens.
- Syndrome of multiple health problems, as well as reproductive function
- Often manifests in the teen or preteen years, with symptoms worsening in adulthood, including one or more of the following:
  - ✓ Androgenic features (acne, facial and body hair)
  - ✓ Obesity or increasing weight
  - ✓ Menstrual irregularities
  - ✓ Mood disorders
- Predisposes women to development of metabolic disorders such as
  - obesity, diabetes, and heart disease, in addition to reproduction dysfunction.

#### Problems for Teens with PCOS in the Healthcare System

- Under-recognition of PCOS in teens by healthcare providers
  - ✓ General lack of attentiveness to early diagnosis in teens
  - ✓ Difficulty in diagnosis due to symptom overlap of other common teen conditions
  - ✓ Tendency toward symptomatic treatment without addressing comprehensive health implications
- Lack of information
  - ✓ Lack of time for adequate individualized counseling
  - ✓ Lack of published materials specific to teen concerns
  - ✓ Teens themselves express fears related to the diagnosis due to receiving inadequate information from providers
  - ✓ Teens report a need to search alternative sources such as internet for information and support
  - ✓ Internet sites often supervised by individuals who are not healthcare providers

This project was intended to fill a gap in the lack of available written information used in healthcare settings about PCOS in teens and young women. The intended use of this guidebook is to augment general counseling done by providers, and to provide a resource of further information for teens and their families for more information.

### Methods and Approach

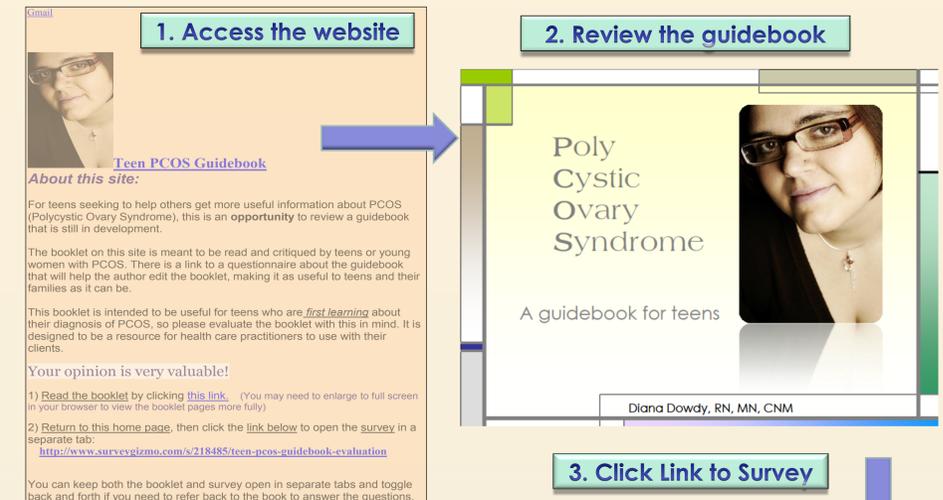
#### Research

- **Review of literature**
  - ✓ Physiology and psychosocial needs of young women with PCOS
  - ✓ Learning needs of teens with PCOS
- **Observation** of communications between teens with PCOS on specific PCOS web support and chat sites.

#### Implementation

- **Guidebook** development, content guided by previous research
- **Survey tool** development to evaluate booklet's content and design
- **IRB approval** obtained\*
- **Webpage** development to house the guidebook, providing a link to **SurveyGizmo™** employed to record and tabulate data
- **Letter of invitation to participate** sent to 4 PCOS sites on the Internet
  - ✓ PCOSupport.org (the Teen PCOS forum)
  - ✓ Facebook™ (3 separate PCOS support sites)

### Online Guidebook Review and Evaluation Steps



### Evaluation

#### Survey

- Demographics (age, geographic location, setting – rural/urban)
- Length of time participant has known she had PCOS
- Type of healthcare provider currently seeing
- Family history of PCOS, diabetes
- BMI information (optional)
- List of other medical problems
- Likert scales evaluating guidebook contents:
  - ✓ Purpose
  - ✓ Wording
  - ✓ Amount of information
  - ✓ Specific page by page content rating
- Open-ended section for comments

The screenshot shows a survey form titled 'PCOS Teen Guidebook Survey - Content of Questions'. It includes demographic questions and Likert scales for evaluating the guidebook's content. The Likert scale options are: Strongly disagree, Disagree, Not sure, Agree, Strongly agree.

### Discussion of Findings

- Findings were reviewed and tabulated May, 2010.
- **Revisions** made to the guidebook based on recommendations from survey results.
- **Guidebook was copyrighted and published**
- **Guidebook distributed to local healthcare professionals**
  - ✓ Pediatricians
  - ✓ Dermatologists
  - ✓ Cosmetic surgeons
  - ✓ Family Practice Providers
- Providers have continued to request these booklets for their clients
- Update and revision of the Guidebook is in progress

\*This Guidebook was developed as a scholarly project, with IRB approval by the University of Alabama in Huntsville, 2010.