Are expanding disease definitions unnecessarily labelling women with PCOS?

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Polycystic ovary syndrome (PCOS)

- **Associated with:**
  - Adverse reproductive outcomes (e.g. infertility, gestational diabetes)
  - Adverse metabolic and cardiovascular outcomes (e.g. metabolic syndrome, insulin resistance and type 2 diabetes mellitus)

- **Symptoms**
  - anovulation
  - menstrual irregularities
  - polycystic ovaries
  - hirsutism
  - Acne
  - alopecia

Image from jeanhailes.org.au
Diagnostic change and impact on prevalence

Expanding diagnostic criteria

- In 2003, the diagnostic criteria was expanded by including polycystic ovaries on ultrasound, requiring 2 out of the 3 for a diagnosis

Increasing rate of diagnosis

- Number of women diagnosed has increased from 4-6.6% to up to 21% of reproductive aged women

(Azziz et al., 2004; Boyle et al., 2012)

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<td>And exclusion of other aetiologies</td>
<td>3) Polycystic ovaries</td>
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Is PCOS being overdiagnosed?
Diagnostic controversy

• Based on expert majority opinion

• Insufficient high quality evidence on long-term follow up or therapeutic benefit to derive an evidence-based definition of the syndrome (Lizneva et al., 2016)

• Polycystic ovaries: a common, age dependent finding
  • Present in 62-84% of women aged 18-30 years from the general population, decreasing to 7% in women aged 41-45 (Johnstone et al., 2010; Duijkers & Klipping, 2010)
Early diagnosis during adolescence

• Features of PCOS overlap with normal symptoms of pubertal development
  • Acne
  • Oligomenorrhea
  • Polycystic ovaries on ultrasound

• No evidence of long-term benefit in identifying PCOS in this age group

  Morris et al., 2016
Diagnosis during young adulthood

Figure 1. Prevalence of PCOS by age group and diagnostic criteria of a community sample from Chengdu, China (12-44 years; Zhuang et al., 2014)
Diagnosis of non-hyperandrogenic phenotypes

- The non-hyperandrogenic phenotypes introduced by expanded criteria have been found to not have the same increased risk of adverse long-term implications as the original hyperandrogenic phenotypes.
Limitations in evidence of treatment benefit

• Existing evidence of low quality

• Referral bias

• No evidence to support rationale of expanding diagnosis
PCOS is associated with psychological burden

Women diagnosed with PCOS have higher levels of:

• Depression and anxiety
• Low self-esteem
• Negative body image
• Disordered eating
• Reduced health related quality of life

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Influence of the disease label ‘polycystic ovary syndrome’ on intention to have an ultrasound and psychosocial outcomes: a randomised online study in young women

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How to move forward

• More adequately powered, carefully phenotyped and multiethnic longitudinal research in unbiased populations

• Focus on improving patient-centred outcomes, not just biochemical markers

• Awareness of the issues in applying a one-size-fits-all diagnostic criteria to heterogeneous presentations of symptoms
Next steps

– Qualitative interviews with clinicians
Aim: To explore the factors that influence decision making around diagnosis and management of PCOS, and examine clinicians’ opinions and experiences regarding the benefits and harms of a diagnosis

– Qualitative interviews with women diagnosed with PCOS
Aim: To explore the benefits and harms of receiving a diagnosis from the woman’s perspective for those with both mild and more severe manifestations of PCOS

– Quantitative investigation using ALSWH data
Aim: To examine whether there is a significant effect of a new diagnosis of PCOS on health-related behaviour, lifestyle and psychosocial outcomes
THANK YOU

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