Debate & Analysis

Polycystic ovarian syndrome:

overdiagnosed and overtreated?

Polycystic ovarian syndrome (PCOS) is a common endocrine disorder affecting women after the menarche. It may be associated with subfertility, type 2 diabetes mellitus, cardiovascular disease (CVD), hirsutism, and acne.

The old National Institute of Health criteria[1] suggest a prevalence of about 5% in this population but the new Rotterdam criteria[2] may result in about 20% of women in this age group having PCOS. Crucially, the Rotterdam criteria only require two of three features: hyperandrogenism, ovulatory dysfunction, and polycystic ovarian morphology on ultrasound scan (USS). So, a woman with oligomenorrhoea and polyfollicular ovaries on USS can be diagnosed as having PCOS. But should more women be labelled and given a 'condition'? What is the evidence of benefit?

There are several reasons why benefit might not follow:

- first, the evidence that those with PCOS have an increased risk of CVD (not an increased risk of risk factors!) is not strong. The best evidence we can find is very weak. It suggests, *'In toto, the present epidemiological data suggest more frequent CVD in classic PCOS, mostly mediated through increased total and abdominal adiposity, and perhaps interacting with PCOS-related hyperandrogenism.'*[3] This paper shows very small absolute gains. These gains are not shown in the group who will be captured by the Rotterdam criteria;
- second, can we help those whom we diagnose with PCOS? Available treatments do not reverse the disorder. But sustained weight loss in those who are obese reduces CVD risk factors, and improves menstrual function and perhaps fertility. However, this reduction is small, and almost certainly confined to those people with PCOS who have hyperandrogenism;
- third, the new Rotterdam criteria are pulling in the people without the hyperandrogenic risk profile;
- fourth, new US scans have higher definition, so are again pulling more people into the diagnosis; and
- fifth, younger people especially have more follicles, which decrease with time.

The underlying fear here is that we are going to expand a disease and not improve the outcome, a classic sign of 'overdiagnosis'.

Including more women in a diagnostic net is not a value-free activity. Each individual will change from a person with a problem to a patient. We know this adversely affects people.[4] Iona Heath, talking of Susan Sontag's 'illness as a metaphor', has said:

'Exploitation of sickness and the fear of sickness corral us into the kingdom of the sick. The method for doing this is a mixture of good intentions, wishful thinking and vested interests.' ('Trainers' workshop, Birmingham, 2014)

DON'T SADDLE PATIENTS WITH UNNECESSARY LABELS

From a justice ethic, sending women (*now patients!*) off for tests deprives others of resources. In giving people a label, we may also increase expectations for treatment of 'abnormalities' and decrease efforts to normalise weight, the primary treatment. However, one paper suggests that a diagnosis of PCOS neither helps nor hinders weightloss.[5]

We are not arguing for underdiagnosis either; a woman seeking pregnancy with oligomenorrhoea (with perhaps other symptoms) should be assessed for PCOS if appropriate. NICE has clear infertility guidelines but weight loss, if obese, improves conception, maternity, and baby outcomes whether PCOS is present or not. Nor must we misdiagnose. There are other causes of oligo- and amenorrhoea — the hyperandrogenic causes (a form of congenital adrenal syndrome and androgen-secreting ovarian tumours) and the non-hyperandrogenic (pregnancy, hypothyroidism, ovarian failure, Cushing's, and acromegaly) — some of which might be captured by the Rotterdam criteria. No, our concern is for the late adolescent who, presenting with acne or an irregular cycle, is sent off for an USS and informed that, they have PCOS, 'with its increased health risks'.

But this is a false dichotomy; as GPs we take a holistic view of our patients, and the best way of doing this is by sharing decisions.[6] This requires us to be wise and knowledgeable, aware of new guidelines and criteria. We should understand that the gains in labelling most women as having PCOS are small, at best confined to those with hyperandrogenism; the Rotterdam criteria will possibly double those labelled and most of these 'new' patients will not be at cardiometabolic risk. This does not stop us compassionately engaging with the (mostly) overweight people who could benefit from lifestyle interventions and treatment of their symptoms.

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