

Young women's psychological distress after a diagnosis of polycystic ovary syndrome or endometriosis

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STUDY QUESTION: Do young women with polycystic ovary syndrome (PCOS) or endometriosis report more psychological distress than their peers without a history of these conditions?

SUMMARY ANSWER: Young women (aged 18–23 years) with PCOS or endometriosis had a greater risk of moderate to severe psychological distress than women without a history of these conditions.

WHAT IS KNOWN ALREADY: Psychological distress appears common among women with PCOS and endometriosis. However, population-based studies that examine the psychological outcomes for adolescents and young women are generally absent from the literature.

STUDY DESIGN, SIZE, DURATION: This is a secondary analysis of data collected from 17 015 young, Australian women participating in a national, longitudinal cohort study. Women were first surveyed in 2012–2013 when they were aged 18–23 years. In 2014, women completed the second survey when they were aged 19–24 years and 11 324 (67%) women responded.

PARTICIPANTS/MATERIALS, SETTING, METHODS: We analysed data from 11 238 women who participated in both Surveys 1 and 2 and who responded to questions about PCOS and endometriosis. Using logistic regression, we compared the odds of moderate to severe psychological distress at Surveys 1 and 2 for women reporting a recent diagnosis (within the last 12 months) of PCOS or endometriosis and women with a pre-existing diagnosis, with that for women without a history of these conditions.

MAIN RESULTS AND THE ROLE OF CHANCE: At Survey 2, around 60% of women reporting a diagnosis of PCOS or endometriosis had moderate to severe levels of psychological distress. Compared to women without a history of these conditions, the odds of moderate to severe psychological distress at Survey 2 were significantly higher for women recently diagnosed with PCOS [Adjusted Odds Ratio (AOR) = 1.62, 95% CI = 1.21–2.18] or endometriosis (AOR = 1.77; 95% CI = 1.20–2.63) and for women with a pre-existing diagnosis of PCOS (AOR = 1.57, 95% CI = 1.30–1.89) or endometriosis (AOR = 1.61; 95% CI = 1.26–2.06). Women recently diagnosed with PCOS or endometriosis also had a greater likelihood of moderate to severe distress in the year prior to their diagnosis. The association between PCOS and psychological distress was attenuated when adjusting for BMI, but hormonal contraceptive use did not attenuate the risk of distress among the women with PCOS or endometriosis.

LIMITATIONS, REASONS FOR CAUTION: All data were self-reported and, therefore, the diagnoses of PCOS or endometriosis were not confirmed by a medical practitioner.

WIDER IMPLICATIONS OF THE FINDINGS: Health professionals should be aware of the potential psychosocial and healthcare needs among young women with these conditions, particularly women with PCOS who are obese. While hormonal contraceptives may help to regulate the hormonal aspects of these conditions, they do not appear to reduce women's psychological distress. Because psychological distress among the young women in this study remained elevated even after diagnosis, this supports the need for multidisciplinary health care to help women adjust to their diagnosis and treatment regimens and facilitate positive, long-term mental health outcomes. Future research that examines medical and psychosocial sources of distress for young women with PCOS and endometriosis is needed.

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Key words: polycystic ovary syndrome / endometriosis / young women / depression / anxiety / obesity / contraceptive use

Introduction

Polycystic ovary syndrome (PCOS) and endometriosis are common conditions and are clinically diagnosed in around 15–20% (Sirmans and Pate, 2013; Lauritsen *et al.*, 2014) and 10–13% of women, respectively (Vigano *et al.*, 2004; Crosignani *et al.*, 2006; Abbas *et al.*, 2012). PCOS and endometriosis are clinically distinct conditions; however, both are associated with extensive physical symptoms and both have significant psychological sequelae. These symptoms typically emerge during adolescence; women with PCOS often experience hormonal and metabolic problems (e.g. irregular periods, hirsutism, acne, fatigue, weight gain) (Teede *et al.*, 2010; Sirmans and Pate, 2013), while menstrual disturbances (e.g. severe pain, irregular and heavy menstrual bleeding) and gastrointestinal/urinary problems are more prominent in women with endometriosis (Culley *et al.*, 2013; De Graaff *et al.*, 2013; Young *et al.*, 2015). Hormonal contraceptives are often used to manage symptoms but do not always provide complete symptom relief, and other medicines may not be safe for long-term use (Crosignani *et al.*, 2006). Invasive gynaecological surgery may be necessary for women who have endometriosis. While the physical symptoms are a common focus in research and practice, there are also significant, long-term psychosocial consequences for women.

PCOS and endometriosis can adversely affect women's lives in different, but also similar ways. PCOS can raise concerns about femininity and body image (Moran *et al.*, 2010; Teede *et al.*, 2010). Pelvic pain among women with endometriosis may impair their social, educational and employment opportunities (Nnoaham *et al.*, 2011; Young *et al.*, 2015). Both conditions can hinder women's sexual relationships, raise concerns about infertility and reduce overall quality of life (Moran *et al.*, 2010; Teede *et al.*, 2010; Bazarganipour *et al.*, 2013; Culley *et al.*, 2013; De Graaff *et al.*, 2013; Young *et al.*, 2015). Although several studies describe the social and psychological impact of PCOS and endometriosis (Benson *et al.*, 2009; Deeks *et al.*, 2011; Dokras *et al.*, 2011; Culley *et al.*, 2013; Hart and Doherty, 2015; Young *et al.*, 2015), most focus on women in their thirties, which excludes the experiences of young women in adolescence and early adulthood. Of the few studies that have examined the psychological outcomes among younger women (<25 years), most relate to PCOS, and studies with women who have endometriosis are generally absent from the literature. Further, results are conflicting; although one study reported that being younger was associated with more symptoms of depression among women with PCOS (Deeks *et al.*, 2011), a study with adolescents did not find an increased risk of depression among girls with PCOS relative to their peers without PCOS (Milsom *et al.*, 2013). Because young adulthood is associated with the emergence of mental health problems, there is a need for large-scale research that examines the extent of mental health issues among young women who have PCOS and endometriosis relative to their peers without these conditions.

This paper uses data from the first two waves of a national, longitudinal cohort study of young Australian women aged 18–23 years to compare

levels of psychological distress among women reporting PCOS or endometriosis to women reporting no history of these conditions. We also compare levels of distress among women reporting a recent diagnosis of PCOS or endometriosis with those among women reporting a pre-existing history of PCOS or endometriosis and examine whether there are changes in women's distress over a 12-month period.

Materials and Methods

The Australian Longitudinal Study on Women's Health (ALSWH) is a national study focusing on the biological, psychological, social and economic factors relevant to women's health (Lee *et al.*, 2005). The original three cohorts of Australian women, who were aged 18–23 years, 45–50 years and 70–75 years when the project began in 1996, are sent self-report surveys on a triennial basis to explore their health and well-being (Lee *et al.*, 2005; Dobson *et al.*, 2015).

In 2012–2013, ALSWH recruited a new cohort of young women born in 1989–1995 and aged 18–23 years when they were first surveyed. Participants were recruited through conventional means (e.g. magazine advertising) and online social media (e.g. Facebook) and completed a web-based survey similar to previous ALSWH surveys (full details reported elsewhere) (Mishra *et al.*, 2014; Loxton *et al.*, 2015). Women were eligible if they lived in Australia and had a valid Medicare (the universal national health insurance scheme) number and if they consented to linking survey data with administrative health data. Further details of the survey methodology are available from the study website (Australian Longitudinal Study on Women's Health (ALSWH)).

Ethics statement

Informed participant consent was implied by survey initiation and provision of contact details and Medicare number to facilitate data linkage. Data were sent to the Australian Department of Human Services to verify participants' Medicare numbers and personal details. All study methods, including the consent procedures, were approved by the Human Research Ethics Committees of the University of Newcastle, the University of Queensland, the Australian Department of Human Services and the Australian Department of Health.

Participants

A total of 17 015 young women born in 1989–1995 completed the first survey in 2012–2013 when they were aged 18–23 years. In 2014, these women were asked to complete the second survey when they were aged 19–24 years and 11 324 (67%) women responded. Women who responded to the follow-up survey were more likely to be older, not married, better educated and have no children compared with non-respondents (all $P < 0.05$). Participants who did not respond to the questions about PCOS or endometriosis at both Survey 1 and Survey 2 ($n = 86$) were excluded, leaving data from 11 238 women available for analysis.

Measures

Psychological distress

Psychological distress was assessed using the validated Kessler 10 (K-10) scale. This is a 10-item scale measuring symptoms of distress in the past 4 weeks on a five-point scale ranging from 'None of the time' to 'All of the

time'. The scale has a theoretical range from 10 to 50 and lower scores indicate better functioning. Scores ranging from 22 to 29 and above 29 are indicative of high and very high levels of distress, respectively (Slade et al., 2011), and suggest moderate to severe depression and/or anxiety (Kessler et al., 2003). In this study, women scoring 22 and above were classified as having moderate to severe psychological distress and women scoring below 22 were classified as having mild or no distress. A US study with a general population sample of adults reported that the K-10 scale had high internal consistency (Cronbach's alpha = 0.93) (Kessler et al., 2003), which was also found in our study with young women (Survey 1 Cronbach's alpha = 0.92; Survey 2 Cronbach's alpha = 0.93). The K-10 is able to distinguish between people with, and without, serious mental health conditions (Kessler et al., 2003) and is widely used as a measure of distress in several international health surveys (Kessler et al., 2002; Furukawa et al., 2003) and in general medical settings (Kessler et al., 2002).

Diagnosis of PCOS or endometriosis

Women were asked, 'Have you ever been diagnosed or treated for?' and chose from a list of 11 health conditions including PCOS and endometriosis at each survey. A transition variable was created for each condition to identify women who had been recently diagnosed with PCOS or endometriosis. Based on the timing and consistency of the first reported diagnosis, women's responses were coded as: 'No-No' (women who had never been diagnosed or treated for PCOS or endometriosis at either survey), 'Yes-Yes' (women who first reported a diagnosis at Survey 1 and re-reported at Survey 2), 'No-Yes' (women who first reported a diagnosis at Survey 2) and 'Yes-No' (women who first reported a diagnosis at Survey 1 but did not re-report at Survey 2).

Covariates

At each survey, sociodemographic information was collected including: age (in years); area of residence based on an index of distance to the nearest urban centre (major cities, regional/remote) (Australian Institute of Health and Welfare (AIHW), 2004); highest level of education (less than year 12, year 12 or equivalent, certificate/diploma, university degree); ability to manage on income (easy/not too bad, difficult some of the time, difficult all of time/impossible); current relationship status (single, married/de facto) and parity (none, ≥ 1). BMI (kg/m^2) was calculated using women's self-reported weight and height, and categorized as underweight/normal weight ($< 25 \text{ kg}/\text{m}^2$), overweight ($25\text{--}29.9 \text{ kg}/\text{m}^2$), obese ($\geq 30 \text{ kg}/\text{m}^2$). Women also reported doctor diagnoses of chronic health conditions (e.g. diabetes, heart disease, hypertension and cancer). Women were also asked about contraceptive use the last time they had vaginal sex and chose from a list of five options: condoms, the pill, Implanon, Mirena, no contraception. Women could also state other forms of contraception used. Only women using hormonal contraceptives (e.g. injection, vaginal ring) were categorized as being hormonal contraceptive users. Women also reported the frequency of menstrual symptoms (premenstrual tension, heavy periods, severe period pain, irregular periods) in the last 12 months. Women reporting symptoms 'often' were categorized as experiencing these symptoms.

Statistical analysis

An exploratory analysis was conducted to examine the proportion of women who reported a diagnosis of PCOS or endometriosis at each survey and the timing of the first reported diagnosis. We then examined differences in sociodemographic and reproductive variables at Survey 1 among women according to the timing of their diagnosis of PCOS or endometriosis using χ^2 tests for categorical variables. The association between PCOS or endometriosis and the presence of moderate to severe psychological distress at Surveys 1 and 2 was examined using logistic regression. Potential confounding variables measured at Survey 1 were added to the models in blocks to assess their

contribution to psychological distress at Surveys 1 and 2: sociodemographic variables (age, marital status, education, ability to manage on income, area of residence, parity), followed by BMI category (kg/m^2) and chronic conditions, and then contraceptive use. Longitudinal logistic regression models using generalized estimating equations were used to assess the association between PCOS or endometriosis and changes in psychological distress adjusting for age, marital status, education, ability to manage on income, area of residence, parity, BMI and contraceptive use. All statistical analyses were performed using the SAS software version 9.4.

Results

Of the 11238 women included in this analysis, 524 (4.66%) reported ever being diagnosed or treated for PCOS at Surveys 1 and 2 (PCOS-PCOS) and 207 (1.84%) first reported being diagnosed or treated for PCOS at Survey 2 (No-PCOS). A further 110 (0.98%) women reported ever being diagnosed or treated for PCOS at Survey 1 but did not re-report the condition at Survey 2 (PCOS-No). For women reporting endometriosis, 298 (2.65%) women reported ever being diagnosed or treated for endometriosis at Surveys 1 and 2 (Endo-Endo) and 115 (1.02%) women first reported this condition at Survey 2 (No-Endo). An additional 89 (0.79%) women reported ever being diagnosed or treated for endometriosis at Survey 1 but did not re-report the condition at Survey 2 (Endo-No).

Sociodemographic and reproductive characteristics

Tables I and II describe the characteristics of young women with PCOS and with endometriosis at Survey 1, respectively. Women who reported ever being diagnosed with PCOS at Survey 1 (PCOS-PCOS) were more likely to be older and to have a graduate certificate/diploma or higher than women who had never been diagnosed. Women who reported a diagnosis of PCOS at either survey or both surveys were more likely to be obese and to have a diagnosis of a chronic condition and less likely to be using a hormonal contraceptive than women who had never been diagnosed. Around half of women in the PCOS-PCOS group reported irregular periods (55.4%); the percentages were slightly lower in the No-PCOS (38.2%) and PCOS-No (40.9%) groups but higher than women in the No-No (17.1%) group. Premenstrual tension, heavy periods and severe period pain were also common among women in the PCOS-PCOS and No-PCOS groups, but not among women in the PCOS-No group who were most similar to women in the No-PCOS group. There were no differences between the groups for area of residence or parity ($P < 0.05$).

Women, who reported a diagnosis of endometriosis in at least one survey, were more likely to be married or living with a partner than women who had never been diagnosed. Women who first reported a diagnosis of endometriosis at Survey 2 (No-Endo) were more likely to have completed a university degree, whereas women whose reporting of endometriosis was inconsistent (Endo-No) were less likely to have a university qualification and more likely to report difficulty managing their income than women who had never been diagnosed. Further, the Endo-No group were more likely to have had a child, to be obese and to have a diagnosis of a chronic health condition compared with women who had never been diagnosed. The majority of women with a history of Endometriosis (Endo-Endo) reported severe period pain (68.5%) and were also more likely to report heavy periods (43.3%)

Table 1 Characteristics (at Survey 1) of women ever, and never, diagnosed with PCOS.

| | No-No, n = 10 397 (92.5%) N (%) | PCOS-PCOS, n = 524 (4.7%) N (%) | No-PCOS, n = 207 (1.8%) N (%) | PCOS-No, n = 110 (1.0%) N (%) | χ^2 | P |
|--------------------------------------|---------------------------------------|---------------------------------------|-------------------------------------|-------------------------------------|----------|---------|
| Age | | | | | | |
| 18–19 | 3296 (31.7) | 119 (22.7) | 65 (31.4) | 28 (25.5) | 30.51 | <0.0001 |
| 20–21 | 3518 (33.8) | 174 (33.2) | 74 (35.7) | 34 (30.9) | | |
| 22–23 | 3583 (34.5) | 231 (44.1) | 68 (32.9) | 48 (43.6) | | |
| Education | | | | | | |
| <Year 12 | 603 (5.8) | 31 (5.9) | 12 (5.8) | 10 (9.1) | 32.80 | 0.0001 |
| Year 12 | 4688 (45.2) | 194 (37.0) | 84 (40.6) | 39 (35.5) | | |
| Certificate/diploma | 2527 (24.4) | 175 (33.4) | 61 (29.5) | 35 (31.8) | | |
| University | 2553 (24.6) | 124 (23.7) | 50 (24.2) | 26 (23.6) | | |
| Ability to manage on income | | | | | | |
| Easy/not too bad | 4257 (41.1) | 179 (34.2) | 65 (31.4) | 39 (35.45) | 37.14 | <0.0001 |
| Difficult some of the time | 3710 (35.8) | 179 (34.2) | 77 (37.2) | 34 (30.9) | | |
| Difficult all of the time/impossible | 2400 (23.2) | 166 (31.7) | 65 (31.4) | 37 (33.6) | | |
| Marital status | | | | | | |
| Single | 7624 (73.5) | 379 (72.3) | 133 (64.3) | 72 (65.5) | 12.53 | 0.006 |
| Married/de facto | 2747 (26.5) | 145 (27.7) | 74 (35.7) | 38 (34.5) | | |
| Area of residence | | | | | | |
| Urban | 7819 (75.4) | 395 (75.4) | 164 (79.6) | 83 (75.5) | 1.93 | 0.59 |
| Rural | 2549 (24.6) | 129 (24.6) | 42 (20.4) | 27 (24.5) | | |
| Parity | | | | | | |
| 0 | 9882 (95.3) | 497 (94.8) | 196 (94.7) | 102 (92.7) | 2.03 | 0.57 |
| ≥ 1 | 484 (4.7) | 27 (5.2) | 11 (5.3) | 8 (7.3) | | |
| BMI | | | | | | |
| ≤24.99 | 7188 (69.6) | 202 (38.8) | 102 (49.5) | 63 (57.3) | 384.77 | <0.0001 |
| 25–29.9 | 1946 (18.8) | 126 (24.2) | 45 (21.8) | 20 (18.2) | | |
| ≥30 | 1191 (11.5) | 193 (37.0) | 59 (28.6) | 27 (24.5) | | |
| Chronic conditions | | | | | | |
| No | 10019 (96.4) | 478 (91.2) | 186 (89.9) | 100 (90.9) | 61.74 | <0.0001 |
| Yes | 378 (3.6) | 46 (8.8) | 21 (10.1) | 10 (9.1) | | |
| Hormonal contraceptive use | | | | | | |
| No | 4109 (39.5) | 261 (49.8) | 105 (50.7) | 59 (53.6) | 147.14 | <0.0001 |
| Yes | 6288 (60.5) | 263 (50.2) | 102 (49.3) | 51 (46.4) | | |
| Premenstrual tension | | | | | | |
| No | 8759 (84.4) | 392 (75.0) | 155 (74.9) | 91 (82.7) | 44.77 | <0.0001 |
| Yes | 1622 (15.6) | 131 (25.0) | 52 (25.1) | 19 (17.3) | | |
| Heavy periods | | | | | | |
| No | 8921 (85.9) | 358 (68.3) | 149 (72.0) | 92 (83.6) | 546.69 | <0.0001 |
| Yes | 1462 (14.1) | 166 (31.7) | 58 (28.0) | 18 (16.4) | | |
| Severe period pain | | | | | | |
| No | 8315 (80.1) | 322 (61.5) | 131 (63.3) | 80 (72.7) | 73.11 | <0.0001 |
| Yes | 2066 (19.9) | 202 (38.5) | 76 (36.7) | 30 (27.3) | | |
| Irregular periods | | | | | | |
| No | 8607 (82.9) | 233 (44.6) | 128 (61.8) | 65 (59.1) | 325.21 | <0.0001 |
| Yes | 1775 (17.1) | 290 (55.4) | 79 (38.2) | 45 (40.9) | | |

Table II Characteristics (at Survey I) of women ever, and never, diagnosed with endometriosis.

| | No-No, n = 10 736 (95.5%) N (%) | Endo-Endo, n = 298 (2.7%) N (%) | No-Endo, n = 115 (1.0%) N (%) | Endo-No, n = 89 (0.8%) N (%) | χ^2 | P |
|--------------------------------------|---------------------------------------|---------------------------------------|-------------------------------------|------------------------------------|----------|---------|
| Age | | | | | | |
| 18–19 | 3383 (31.5) | 71 (23.8) | 32 (27.8) | 22 (24.7) | 12.35 | 0.05 |
| 20–21 | 3623 (33.7) | 103 (34.6) | 43 (37.4) | 31 (34.8) | | |
| 22–23 | 3730 (34.7) | 124 (41.6) | 40 (34.8) | 36 (40.4) | | |
| Education | | | | | | |
| <Year 12 | 616 (5.8) | 23 (7.7) | 11 (9.6) | 6 (6.7) | 62.30 | <0.0001 |
| Year 12 | 4837 (45.2) | 101 (33.9) | 44 (38.6) | 23 (25.8) | | |
| Certificate/diploma | 2620 (24.5) | 106 (35.6) | 27 (23.7) | 45 (50.6) | | |
| University | 2638 (24.6) | 68 (22.8) | 32 (28.1) | 15 (16.9) | | |
| Ability to manage on income | | | | | | |
| Easy/not too bad | 4376 (40.9) | 95 (31.9) | 39 (34.2) | 30 (33.7) | 16.11 | 0.01 |
| Difficult some of the time | 3810 (35.6) | 117 (39.3) | 42 (36.8) | 31 (34.8) | | |
| Difficult all of the time/impossible | 2521 (23.6) | 86 (28.9) | 33 (29.0) | 28 (31.5) | | |
| Marital status | | | | | | |
| Single | 7904 (73.8) | 181 (60.7) | 70 (61.4) | 53 (59.6) | 42.06 | <0.0001 |
| Married/de facto | 2807 (26.2) | 117 (39.3) | 44 (38.6) | 36 (40.4) | | |
| Area of residence | | | | | | |
| Urban | 8094 (75.6) | 227 (76.7) | 78 (68.4) | 62 (69.7) | 4.99 | 0.17 |
| Rural | 2615 (24.4) | 69 (23.3) | 36 (31.6) | 27 (30.3) | | |
| Parity | | | | | | |
| 0 | 10217 (95.4) | 278 (93.3) | 108 (94.7) | 74 (83.1) | 32.33 | <0.0001 |
| ≥1 | 489 (4.6) | 20 (6.7) | 6 (5.3) | 15 (16.9) | | |
| BMI | | | | | | |
| ≤24.99 | 7255 (68.0) | 185 (62.5) | 66 (57.9) | 49 (55.1) | 17.86 | 0.007 |
| 25–29.9 | 2027 (19.0) | 63 (21.3) | 26 (22.8) | 21 (23.6) | | |
| ≥30 | 1381 (13.0) | 48 (16.2) | 22 (19.3) | 19 (21.3) | | |
| Chronic conditions | | | | | | |
| No | 10327 (96.2) | 276 (92.6) | 102 (88.7) | 78 (87.6) | 41.51 | <0.0001 |
| Yes | 409 (3.8) | 22 (7.4) | 13 (11.3) | 11 (12.4) | | |
| Hormonal contraceptive use | | | | | | |
| No | 4367 (40.7) | 92 (30.9) | 48 (41.7) | 27 (30.3) | 15.40 | 0.002 |
| Yes | 6369 (59.3) | 206 (69.1) | 67 (58.3) | 62 (69.7) | | |
| Premenstrual tension | | | | | | |
| No | 9079 (84.7) | 185 (62.1) | 71 (61.7) | 62 (69.7) | 163.80 | <0.0001 |
| Yes | 1640 (15.3) | 113 (37.9) | 44 (38.3) | 27 (30.3) | | |
| Heavy periods | | | | | | |
| No | 9209 (85.9) | 169 (56.7) | 78 (67.8) | 64 (71.9) | 229.67 | <0.0001 |
| Yes | 1513 (14.1) | 129 (43.3) | 37 (32.2) | 25 (28.1) | | |
| Severe period pain | | | | | | |
| No | 8664 (80.8) | 94 (31.5) | 47 (40.9) | 43 (48.3) | 574.00 | <0.0001 |
| Yes | 2056 (19.2) | 204 (68.5) | 68 (59.1) | 46 (51.7) | | |
| Irregular periods | | | | | | |
| No | 8706 (81.2) | 184 (61.7) | 78 (67.8) | 65 (73.0) | 85.15 | <0.0001 |
| Yes | 2014 (18.8) | 114 (38.3) | 37 (32.2) | 24 (27.0) | | |

and irregular periods (38.3%) than women who had never been diagnosed (19.2, 14.1 and 18.8%, respectively). A large percentage of women in the No-Endo group also reported severe period pain (59.1%), heavy periods (32.2%) and irregular periods (32.2%) as did women in the Endo-No group (51.7, 28.1, and 27.0%, respectively) but the percentages were noticeably lower than those for women in the Endo-Endo group. There were no differences between the groups for age or area of residence.

Psychological distress among women with gynaecological conditions

At both Surveys 1 and 2, women reporting a history of PCOS (PCOS-PCOS) and women reporting a first diagnosis of PCOS by Survey 2 (No-PCOS) had greater odds of moderate to severe psychological distress than women who had never been diagnosed (see Table III). However, the odds of moderate to severe psychological distress for women who did not re-report their diagnosis of PCOS at Survey 2 (PCOS-No) were not significantly different from women who had never been diagnosed. Adjustment for sociodemographic characteristics did not make substantive changes to the results. However, the association between PCOS and psychological distress was attenuated when adding BMI to the model (see Table IV, Model 3). Chronic conditions were not significantly associated with distress and were not retained for future analyses (results not shown). The results were essentially unchanged when adding contraceptive use at the final step (see Model 4, Table IV). Longitudinal analyses adjusting for confounding variables showed that psychological distress did not significantly change between the surveys for any of the conditions groups, $df(3)$, $\chi^2 = 1.26$, $P = 0.74$.

At both Surveys 1 and 2, the odds of moderate to severe psychological distress were also significantly higher among women who had a history of endometriosis (Endo-Endo) and women reporting a first diagnosis of endometriosis at Survey 2 (No-Endo) relative to women who had never been diagnosed (Table V). Compared to women who had never been diagnosed with endometriosis, the risk of moderate to severe psychological distress was significantly higher for women in the Endo-No group at Survey 1 but not at Survey 2. Adjustment for sociodemographic characteristics, BMI and contraceptive use did not make statistically significant changes to the results (Table VI). Chronic conditions were not significantly associated with distress and were not retained for future analyses (results not shown). Further, longitudinal analyses adjusting for sociodemographic characteristics, BMI and contraceptive use showed that psychological distress did not significantly change over time within the endometriosis groups, $df(3)$, $\chi^2 = 1.92$, $P = 0.59$.

Discussion

This study used a large, nationally representative sample of young women to compare psychological distress among women recently diagnosed with PCOS or endometriosis to women with a history, and with no report, of these conditions. Using two waves of survey data collected 12 months apart, we were also able to examine whether there were significant changes in women's distress before and after diagnosis. To date, this study is the first Australian, population-based study to focus specifically on the psychological outcomes of young women with these conditions.

Regardless of the timing of the diagnosis, around 60% of women reporting a diagnosis of PCOS or endometriosis had moderate to severe levels of psychological distress, indicating probable moderate to severe depression and/or anxiety. Our findings support previous studies reporting high levels of psychological distress among women who have PCOS (Deeks *et al.*, 2011; Veltman-Verhulst *et al.*, 2012) or endometriosis (Gao *et al.*, 2006; De Graaff *et al.*, 2013). The findings reinforce the evidence-based guidelines for PCOS, which recognize the need to undertake routine screening for mental health and treat mood disorders to improve women's quality of life (Teede *et al.*, 2011).

In this study, young women recently diagnosed with PCOS or endometriosis had a greater risk of moderate to severe distress in the year prior to diagnosis than women without these conditions. Delays in diagnosis are common for women with these conditions and have been shown to contribute to women's distress (Deeks *et al.*, 2011; Nnoaham *et al.*, 2011; Young *et al.*, 2015). In young women, establishing a definitive diagnosis of PCOS (menstrual cycle irregularity, hirsutism, polycystic change on ultrasound) or endometriosis (dysmenorrhea) can be particularly challenging. The symptoms that characterize these conditions are also consistent with normal adolescent changes, and may be easily confused with other conditions, or not recognized by doctors, which may increase women's distress. Ambiguity in clinical diagnostic criteria for PCOS often necessitates specialist knowledge and pathology investigations, and for endometriosis diagnostic imaging or surgery (e.g. ultrasound, laparoscopy) is required to make definitive diagnoses (Sirmans and Pate, 2013). These can all negatively affect women's well-being in the time prior to diagnosis. Overall, young women need access to health professionals who have the time, and skills, to assess their symptoms and determine whether they are experiencing 'normal' adolescence or if their symptoms are indicative of a more serious condition.

However, although a diagnosis offers an explanation for symptoms and may provide a sense of relief and validation for some women (Culley *et al.*, 2013), for others a diagnosis may not acutely alleviate their overall distress. In our study, the risk of distress remained high for women with PCOS or endometriosis who were newly diagnosed and who consistently reported a pre-existing diagnosis. A diagnosis may create new sources of distress for women including 'uncertainties' and concerns regarding future health and well-being (Moran *et al.*, 2010; Culley *et al.*, 2013). Treatment side-effects, the potential need for surgery and the associated financial costs may also be sources of considerable anxiety for women who have these conditions (Fuldeore *et al.*, 2015; Young *et al.*, 2015). Women with PCOS also report dissatisfaction with the diagnostic experience and inadequate education and information provision (Gibson-Helm *et al.*, 2014). Women's health concerns, when combined with inadequate information and support following diagnosis, may exacerbate their already high levels of distress (Culley *et al.*, 2013), and highlight the need for support and education around the time of diagnosis.

Although we are unable to definitively determine the sources of distress for these women, adjustment for BMI attenuated the risk of distress for women who had PCOS, but not for women with endometriosis. Around 70% of Australian women diagnosed with PCOS are overweight or obese (Teede *et al.*, 2013) and young women who are obese have a greater risk of psychological distress (Kubzansky *et al.*, 2012). However, because obesity exacerbates PCOS severity (Teede *et al.*, 2010), this may also explain the findings. Women with PCOS who are

Table III Association between PCOS and the odds of moderate to severe psychological distress at Surveys 1 and 2 ($n = 11\,238$).

| Group | Survey 1 | | | P | Survey 2 | | | P |
|-----------|--------------------|--------------------------|---|---------|--------------------|--------------------------|---|---------|
| | None–mild n (%) | Moderate–severe n (%) | S1 moderate–severe distress Unadjusted OR (95% CI) | | None–mild n (%) | Moderate–severe n (%) | S2 moderate–severe distress Unadjusted OR (95% CI) | |
| No-No | 5515 (53.2) | 4862 (46.9) | 1 | | 5580 (54.4) | 4671 (45.6) | 1 | |
| PCOS-PCOS | 201 (38.4) | 323 (61.6) | 1.82 (1.52–2.18) | <0.0001 | 207 (40.0) | 311 (60.0) | 1.80 (1.50–2.15) | <0.0001 |
| No-PCOS | 82 (39.6) | 125 (60.4) | 1.73 (1.31–2.29) | 0.0001 | 78 (38.8) | 123 (61.2) | 1.88 (1.42–2.51) | <0.0001 |
| PCOS-No | 63 (57.3) | 47 (42.7) | 0.85 (0.58–1.24) | 0.39 | 64 (58.7) | 45 (41.3) | 0.84 (0.57–1.23) | 0.37 |

Table IV Association between PCOS and odds of moderate to severe psychological distress at Survey 2 ($n = 11\,238$), adjusting for sociodemographic characteristics, BMI and contraceptive use.

| Group | None–mild n (%) | Moderate–severe psychological distress | | | | |
|-----------|--------------------|--|-----------------------------------|--|--|--|
| | | Moderate–severe n (%) | Model 1 Unadjusted OR (95% CI) | Model 2 Sociodemographics Adjusted ^a OR (95% CI) | Model 3 BMI Adjusted ^b OR (95% CI) | Model 4 Contraception Adjusted ^c OR (95% CI) |
| No-No | 5580 (54.4) | 4671 (45.6) | 1 | 1 | 1 | 1 |
| PCOS-PCOS | 207 (40.0) | 311 (60.0) | 1.80 (1.50–2.15) | 1.75 (1.45–2.11) | 1.57 (1.30–1.89) | 1.57 (1.30–1.89) |
| No-PCOS | 78 (38.8) | 123 (61.2) | 1.88 (1.42–2.51) | 1.77 (1.32–2.38) | 1.63 (1.21–2.19) | 1.62 (1.21–2.18) |
| PCOS-No | 64 (58.7) | 45 (41.3) | 0.84 (0.57–1.23) | 0.77 (0.52–1.14) | 0.74 (0.50–1.10) | 0.74 (0.50–1.10) |

^aAdjusted for age (in years), education, ability to manage on income, area of residence, marital status and parity at S1.

^bAdjusted for age (in years), education, ability to manage on income, area of residence, marital status and parity and BMI (kg/m^2) at S1.

^cAdjusted for age (in years), education, ability to manage on income, area of residence, marital status, parity, BMI (kg/m^2) and contraceptive use at S1.

Table V Association between endometriosis and odds of moderate to severe psychological distress at Surveys 1 and 2 ($n = 11\,238$).

| Group | Survey 1 | | S1 moderate–severe distress Unadjusted OR (95% CI) | P | Survey 2 | | S2 moderate–severe distress Unadjusted OR (95% CI) | P |
|-----------|--------------------|--------------------------|---|--------|--------------------|--------------------------|---|---------|
| | None–mild n (%) | Moderate–severe n (%) | | | None–mild n (%) | Moderate–severe n (%) | | |
| No-No | 5660 (52.8) | 5057 (47.2) | 1 | | 5721 (54.1) | 4861 (45.9) | 1 | |
| Endo-Endo | 126 (42.3) | 172 (57.7) | 1.53 (1.21–1.93) | 0.0004 | 120 (40.8) | 174 (59.2) | 1.71 (1.35–2.16) | <0.0001 |
| No-Endo | 42 (36.8) | 72 (63.2) | 1.92 (1.31–2.81) | 0.0008 | 45 (39.5) | 69 (60.5) | 1.81 (1.24–2.63) | 0.002 |
| Endo-No | 33 (37.1) | 56 (62.9) | 1.90 (1.23–2.93) | 0.004 | 43 (48.3) | 46 (51.7) | 1.26 (0.83–1.91) | 0.28 |

overweight or obese may have greater health and psychosocial needs, which increases their levels of distress. Supportive interventions that offer strategies to women to prevent weight gain while also addressing their psychological needs may be beneficial.

High levels of distress may also relate to the difficulties coping with extensive physical symptoms. Menstrual symptoms including severe pain

and irregular and heavy periods were frequently reported, particularly by women with endometriosis. There is also evidence to suggest that pelvic pain may be an important determinant of distress among women with endometriosis (Jones et al., 2002; Giudice, 2010; Simoens et al., 2012; Facchin et al., 2015). Hormonal contraceptives are an effective, and recommended, form of treatment for women's hormonal

Table VI Association between endometriosis and odds of moderate to severe psychological distress at Survey 2 ($n = 11\,238$), adjusting for sociodemographic characteristics, BMI and contraceptive use.

| Group | None–mild <i>n</i> (%) | Moderate–severe <i>n</i> (%) | Moderate–severe psychological distress | | | |
|-----------|---------------------------|---------------------------------|--|--|--|--|
| | | | Model 1 Unadjusted OR (95% CI) | Model 2 Sociodemographics Adjusted ^a OR (95% CI) | Model 3 BMI Adjusted ^b OR (95% CI) | Model 4 Contraception Adjusted ^c OR (95% CI) |
| No–No | 5721 (54.1) | 4861 (45.9) | | | | |
| Endo–Endo | 120 (40.8) | 174 (59.2) | 1.71 (1.35–2.16) | 1.64 (1.29–2.09) | 1.61 (1.26–2.06) | 1.61 (1.26–2.06) |
| No–Endo | 45 (39.5) | 69 (60.5) | 1.81 (1.24–2.63) | 1.80 (1.21–2.66) | 1.78 (1.20–2.63) | 1.77 (1.20–2.63) |
| Endo–No | 43 (48.3) | 46 (51.7) | 1.26 (0.83–1.91) | 1.16 (0.75–1.78) | 1.13 (0.73–1.74) | 1.13 (0.74–1.74) |

^aAdjusted for age (in years), education, ability to manage on income, area of residence, marital status and parity at S1.

^bAdjusted for age (in years), education, ability to manage on income, area of residence, marital status, parity and BMI (kg/m^2) at S1.

^cAdjusted for age (in years), education, ability to manage on income, area of residence, marital status, parity, BMI (kg/m^2) and contraceptive use at S1.

symptoms (Setji and Brown, 2014). However, we found that hormonal contraceptive use was lower among women with these conditions than those without. A lower rate of contraceptive use among young women with PCOS (aged 28–33 years) has also been reported in another ALSWH analysis with a different sample of young women (born in 1973–1978). The reason for this is not understood but may relate to personal choice, side-effects, lack of health professional knowledge or inadequate education (Joham *et al.*, 2014). Importantly, we note that hormonal contraception did not attenuate, or exacerbate, the risk of distress among the women; a finding consistent with another study of women diagnosed with PCOS (Cinar *et al.*, 2012). Other social (e.g. social support) and healthcare factors (e.g. information needs) may, therefore, be important for women with PCOS and endometriosis (Culley *et al.*, 2013; Roos-Eysbouts *et al.*, 2015), suggesting the need for a 'holistic' approach to treatment and management.

Research that examines the sources of distress for young women with PCOS and endometriosis will assist with the development of supportive interventions. While symptoms of PCOS and endometriosis are distressing for many women, a better understanding of the sources of women's distress is needed. Management of distress is important as distress may be a barrier to help-seeking for young women in the future. Another study of young, Australian women with PCOS and endometriosis (aged 28–33 years) found that women were less likely to seek medical advice for fertility problems if they were also experiencing symptoms of depression (Herbert *et al.*, 2010). Multidisciplinary woman-centred care is, therefore, important to help to maintain, and improve, women's quality of life (Teede *et al.*, 2011).

The results of this study are based on a large, national sample of young, Australian women who were aged 18–23 years at the first survey. The women are broadly representative of the Australian population in that age range (Mishra *et al.*, 2014), which increases the extent to which the results will generalize to other young women. Our study also includes a large comparison group of women without a history of diagnosed or self-reported PCOS or endometriosis and we were able to adjust for key sociodemographic characteristics relevant to women's psychological health. The use of population-based data rather than clinic-based data may also be more representative of those women with PCOS or endometriosis.

However, a limitation of this study is that we relied on women to accurately report their diagnosis of PCOS or endometriosis, as well as BMI, distress and contraception use. Although there is evidence to suggest that women can reliably report reproductive events and associated treatments (Herbert *et al.*, 2012), we did find a small number of women who reported a diagnosis of PCOS or endometriosis at Survey 1 but did not re-report the diagnosis at Survey 2. It is possible that these women were treated for these conditions following their diagnosis and were asymptomatic or did not have severe symptoms by Survey 2. Alternatively, the inconsistencies in women's responses within the 12-month period might also reflect a changed diagnosis following specialist evaluation, reporting errors or recall bias.

It is also important to acknowledge the high overall rates of psychological distress in this sample of young women. A large proportion of women without PCOS or endometriosis also had moderate to severe levels of distress. A recent meta-analysis described modest, but significant differences in symptoms of depression and anxiety among women with and without PCOS (Barry *et al.*, 2011) and our results would support these findings. However, another review of the literature found that depressive symptoms were elevated but within the normal range (Veltman-Verhulst *et al.*, 2012). The conflicting findings may reflect the considerable heterogeneity in women's psychological outcomes and the need for more large-scale, longitudinal research.

Using representative data collected from a population-based sample of young Australian women, this study demonstrates very high levels of psychological distress among women with PCOS and endometriosis. Health professionals should be aware of the potential psychological distress among young women with these conditions and consider that there may be greater health and psychosocial needs for women with PCOS who are overweight or obese. The findings support Australian evidenced-based guidelines for PCOS that recommend routine mental health screening to ensure that appropriate referral pathways are available to women (Teede *et al.*, 2011). Further, the finding that psychological distress was not dependent on the timing of the diagnosis offers strong evidence for the need to make mental health assessments part of the spectrum of ongoing healthcare for women seeking care for hormonal/menstrual symptoms to ensure adequate education and support at diagnosis.

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Authors' roles

I.J.R. made substantial contributions to the conception and design of the study and conducted the statistical analyses and drafted the manuscript. H.T. provided clinical expertise and contributed to interpretation of the results and critical revision of the manuscript for intellectual content. J.L., G.D.M. and A.J.D. made substantial contributions to the conception and design of the study, the acquisition of the data, interpretation of the results and critical revision of the manuscript for intellectual content. All authors read and approved the final manuscript.

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Conflict of interest

The authors declare that no competing interests exist.

References

- Abbas S, Ihle P, Koster I, Schubert I. Prevalence and incidence of diagnosed endometriosis and risk of endometriosis in patients with endometriosis-related symptoms: findings from a statutory health insurance-based cohort in Germany. *Eur J Obstet Gynecol Reprod Biol* 2012;**160**:79–83.
- Australian Institute of Health and Welfare (AIHW). *Rural, Regional and Remote Health: A Guide to Remoteness Classifications*. Canberra: AIHW, 2004.
- Australian Longitudinal Study on Women's Health (ALSWH). Retrieved October 2014, from <http://alswh.org.au/for-participants/1989-95-cohort>.
- Barry JA, Kuczmierczyk AR, Hardiman PJ. Anxiety and depression in polycystic ovary syndrome: a systematic review and meta-analysis. *Hum Reprod* 2011;**26**:2442–2451.
- Bazarganipour F, Ziaei S, Montazeri A, Foroozanfard F, Kazemnejad A, Faghihzadeh S. Predictive factors of health-related quality of life in patients with polycystic ovary syndrome: a structural equation modeling approach. *Fertil Steril* 2013;**100**:1389–1396.
- Benson S, Hahn S, Tan S, Mann K, Janssen OE, Schedlowski M, Elsenbruch S. Prevalence and implications of anxiety in polycystic ovary syndrome: results of an internet-based survey in Germany. *Hum Reprod* 2009;**24**:1446–1451.
- Cinar N, Harmanci A, Demir B, Yildiz BO. Effect of an oral contraceptive on emotional distress, anxiety and depression of women with polycystic ovary syndrome: a prospective study. *Hum Reprod* 2012;**27**:1840–1845.
- Crosignani P, Olive D, Bergqvist A, Luciano A. Advances in the management of endometriosis: an update for clinicians. *Hum Reprod Update* 2006;**12**:179–189.
- Culley L, Law C, Hudson N, Denny E, Mitchell H, Baumgarten M, Raine-Fenning N. The social and psychological impact of endometriosis on women's lives: a critical narrative review. *Hum Reprod Update* 2013;**19**:625–639.
- De Graaff AA, D'Hooghe TM, Dunselman GAJ, Dirksen CD, Hummelshoj L, Consortium WE, Simoons S. The significant effect of endometriosis on physical, mental and social wellbeing: results from an international cross-sectional survey. *Hum Reprod* 2013;**28**:2677–2685.
- Deeks AA, Gibson-Helm ME, Paul E, Teede HJ. Is having polycystic ovary syndrome a predictor of poor psychological function including anxiety and depression? *Hum Reprod* 2011;**26**:1399–1407.
- Dobson AJ, Hockey R, Brown WJ, Byles JE, Loxton DJ, McLaughlin D, Tooth LR, Mishra GD. Cohort profile update: Australian longitudinal study on women's health. *Int J Epidemiol* 2015;**44**:1547–1547f.
- 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**:145–152.
- Facchin F, Barbara G, Saita E, Mosconi P, Roberto A, Fedele L, Vercellini P. Impact of endometriosis on quality of life and mental health: pelvic pain makes the difference. *J Psychosom Obstet Gynaecol* 2015;**36**:135–141.
- Fuldeore M, Yang H, Du EX, Soliman AM, Wu EQ, Winkel C. Healthcare utilization and costs in women diagnosed with endometriosis before and after diagnosis: a longitudinal analysis of claims databases. *Fertil Steril* 2015;**103**:163–171.
- Furukawa TA, Kessler RC, Slade T, Andrews G. The performance of the K6 and K10 screening scales for psychological distress in the Australian National Survey of Mental Health and Well-Being. *Psychol Med* 2003;**33**:357–362.
- Gao X, Yeh Y-C, Outley J, Simon J, Botteman M, Spalding J. Health-related quality of life burden of women with endometriosis: a literature review. *Curr Med Res Opin* 2006;**22**:1787–1797.
- Gibson-Helm ME, Lucas IM, Boyle JA, Teede HJ. Women's experiences of polycystic ovary syndrome diagnosis. *Fam Pract* 2014;**31**:545–549.
- Giudice LC. Endometriosis. *N Engl J Med* 2010;**362**:2389–2398.
- 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**:911–919.
- Herbert DL, Lucke JC, Dobson AJ. Depression: an emotional obstacle to seeking medical advice for infertility. *Fertil Steril* 2010;**94**:1817–1821.
- Herbert D, Lucke J, Dobson A. Agreement between self-reported use of in vitro fertilization or ovulation induction, and medical insurance claims in Australian women aged 28–36 years. *Hum Reprod* 2012;**27**:2823–2828.
- Joham AE, Boyle JA, Ranasinha S, Zoungas S, Teede HJ. Contraception use and pregnancy outcomes in women with polycystic ovary syndrome: data from the Australian Longitudinal Study on Women's Health. *Hum Reprod* 2014;**29**:802–808.
- Jones GL, Kennedy SH, Jenkinson C. Health-related quality of life measurement in women with common benign gynecologic conditions: a systematic review. *Am J Obstet Gynecol* 2002;**187**:501–511.
- Kessler RC, Andrews G, Colpe LJ, Hiripi E, Mroczek DK, Normand SL, Walters EE, Zaslavsky AM. Short screening scales to monitor population prevalences and trends in non-specific psychological distress. *Psychol Med* 2002;**32**:959–976.
- Kessler RC, Barker PR, Colpe LJ, Epstein JF, Gfroerer JC, Hiripi E, Howes MJ, Normand SL, Manderscheid RW, Walters EE et al. Screening for serious mental illness in the general population. *Arch Gen Psychiatry* 2003;**60**:184–189.
- Kubzansky L, Gilthorpe M, Goodman E. A prospective study of psychological distress and weight status in adolescents/young adults. *Ann Behav Med* 2012;**3**:219–228.

- Lauritsen MP, Bentzen JG, Pinborg A, Loft A, Forman JL, Thuesen LL, Cohen A, Hougaard DM, Nyboe Andersen A. The prevalence of polycystic ovary syndrome in a normal population according to the Rotterdam criteria versus revised criteria including anti-Müllerian hormone. *Hum Reprod* 2014;**29**:791–801.
- Lee C, Dobson AJ, Brown WJ, Bryson L, Byles J, Warner-Smith P, Young AF. Cohort profile: the Australian longitudinal study on women's health. *Int J Epidemiol* 2005;**34**:987–991.
- Loxton D, Powers J, Anderson AE, Townsend N, Harris ML, Tuckerman R, Pease S, Mishra G, Byles J. Online and offline recruitment of young women for a longitudinal health survey: findings from the Australian longitudinal study on women's health 1989–1995 cohort. *J Med Internet Res* 2015; **17**:e109.
- Milsom SR, Nair SM, Ogilvie CM, Stewart JM, Merry SN. Polycystic ovary syndrome and depression in New Zealand adolescents. *J Pediatr Adolesc Gynecol* 2013;**26**:142–147.
- Mishra GD, Hockey R, Powers J, Loxton D, Tooth L, Rowlands I, Byles J, Dobson A. Recruitment via the Internet and social networking sites: the 1989–1995 cohort of the Australian Longitudinal Study on Women's Health. *J Med Internet Res* 2014;**16**:e279.
- Moran L, Gibson-Helm M, Teede H, Deeks A. Polycystic ovary syndrome: a biopsychosocial understanding in young women to improve knowledge and treatment options. *J Psychosom Obstet Gynaecol* 2010;**31**:24–31.
- Nnoaham KE, Hummelshoj L, Webster P, d'Hooghe T, de Cicco Nardone F, de Cicco Nardone C, Jenkinson C, Kennedy SH, Zondervan KT. Impact of endometriosis on quality of life and work productivity: a multicenter study across ten countries. *Fertil Steril* 2011;**96**:366–373.e368.
- Roos-Eysbouts Y, De Bie-Rocks B, Van Dijk J, Nap AWW. Characteristics, expectations and needs of the Dutch endometriosis society members. *Gynecol Obstet Invest* 2015;**79**:234–238.
- Setji TL, Brown AJ. Polycystic ovary syndrome: update on diagnosis and treatment. *Am J Med* 2014;**127**:912–919.
- Simoens S, Dunselman G, Dirksen C, Hummelshoj L, Bokor A, Brandes I, Brodzky V, Canis M, Colombo GL, DeLeire T et al. The burden of endometriosis: costs and quality of life of women with endometriosis and treated in referral centres. *Hum Reprod* 2012;**27**:1292–1299.
- Sirmans SM, Pate KA. Epidemiology, diagnosis, and management of polycystic ovary syndrome. *Clin Epidemiol* 2013;**6**:1–13.
- Slade T, Grove R, Burgess P. Kessler psychological distress scale: normative data from the 2007 Australian National Survey of Mental Health and Wellbeing. *Aust N Z J Psychiatry* 2011;**45**:308–316.
- 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.
- Teede HJ, Misso ML, Deeks AA, Moran LJ, Stuckey BG, Wong JL, Norman RJ, Costello MF. Assessment and management of polycystic ovary syndrome: summary of an evidence-based guideline. *Med J Aust* 2011;**195**:S65–112.
- Teede HJ, Joham AE, Paul E, Moran LJ, Loxton D, Jolley D, Lombard C. Longitudinal weight gain in women identified with polycystic ovary syndrome: results of an observational study in young women. *Obesity (Silver Spring)* 2013;**21**:1526–1532.
- Veltman-Verhulst SM, Boivin J, Eijkemans MJ, Fauser BJ. 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**:638–651.
- Vigano P, Parazzini F, Somigliana E, Vercellini P. Endometriosis: epidemiology and aetiological factors. *Best Pract Res Clin Obstet Gynaecol* 2004; **18**:177–200.
- Young K, Fisher J, Kirkman M. Women's experiences of endometriosis: a systematic review and synthesis of qualitative research. *J Fam Plann Reprod Health Care* 2015;**41**:225–234.