

## Abstract

**Background** Polycystic ovary syndrome (PCOS) is a common endocrine condition associated with hyperandrogenism, infertility and metabolic dysfunction. Weight management through diet and lifestyle modifications are fundamental to its management, however, presently there are no official dietary guidelines. This study aimed to explore the dietary and lifestyle strategies followed by women with PCOS and the contribution of dietitians to its management.

**Methods** A questionnaire was completed by 105 UK dietitians focused on the service provided and a patient questionnaire and 7-day food diary were completed by women with PCOS (n=206 and n=196 respectively). Food diaries were analysed for energy and macronutrient intake and the questionnaire focused on the dietary advice received.

**Results** Advice provided by dietitians focused on a reduction in energy intake (78%) and dietary glycaemic index (77%), often in combination. Of the women with PCOS who were following a diet specifically for their PCOS (57%), regimes included low glycaemic index (34%), weight loss diets (16%) or a combination (26%). Of interest, 73% of overweight women were not following a diet to promote weight loss. Nutritional information predominately came from books, with only 15% of women having seen a dietitian. Eighty four percent of women with PCOS who had increased physical activity (48%) self reported an improvement in their symptoms.

**Conclusions** Women with PCOS recognise the importance of diet, but few received dietary advice from a registered dietitian. The dietary information women with PCOS received was often from an unregulated source. A consensus statement of evidence based dietary advice for women with PCOS is needed and would be a useful resource for dietitians.

## Introduction:

Polycystic ovary syndrome (PCOS) is the most common endocrine disorder in women of reproductive age, affecting up to 10% of women (Franks, 1995, Lindholm et al., 2008). The clinical and biochemical features of the syndrome are heterogeneous, including menstrual irregularity and fertility problems, excess hair and acne (Diamanti-Kandarakis, 2008). Women with PCOS are also more likely to be overweight and have an increased risk of metabolic syndrome, type 2 diabetes and cardiovascular disease (Dokras, 2008, Ehrmann et al., 1999). Approximately 33% of UK women with PCOS are obese (Barr et al., 2007) compared with 20% of women in the general population (Ruston et al., 2004).

Although the exact aetiology of PCOS is unknown it involves a combination of genetic and environmental factors (Franks et al., 2006). Insulin resistance, with compensatory hyperinsulinaemia is considered a key factor in the development of symptoms. Hyperinsulinaemia is known to stimulate ovarian androgen production and decrease hepatic sex hormone-binding globulin, resulting in hyperandrogenism and the associated clinical features of PCOS (Galluzzo, 2008). Treatment for PCOS includes diet and lifestyle changes to promote a healthy body mass index (BMI) and reduce hyperinsulinaemia. Specific medications, such as metformin, are used to manage the presenting symptoms; at present there is no cure. Several authors have highlighted the importance of weight management, through diet and lifestyle modifications, in the management of PCOS (Balen et al., 2006, Cussons et al., 2005, The Thessaloniki ESHRE/ ASRM- sponsored PCOS Consensus Workshop Group, 2008).

To date, dietary management of PCOS has focused on weight loss in overweight women, with research showing that weight loss of as little as 5% can reduce insulin levels, improve menstrual function and reduce serum testosterone (Moran et al., 2003, Stamets et al., 2004, Qublan et al., 2007). Due to the increased prevalence of obesity, insulin resistance and subsequent hyperinsulinaemia in women with PCOS, dietary management should also focus on minimising

the risk of diabetes and cardiovascular disease. The Diabetes Prevention Program (2002) and Finnish Diabetes Prevention study (2003) have both shown that positive changes to diet and lifestyle are successful in preventing diabetes in both men and women (Lindstrom et al., 2003, Diabetes Prevention Program Research Group, 2002). Lifestyle management is important in all patients with PCOS, not just the overweight, however there is a paucity of research for the appropriate lifestyle management of lean women with PCOS.

At present there are no published dietary guidelines or consensus statements for the dietary management of women with PCOS by a recognised organisation in the UK or elsewhere in the world. The 4<sup>th</sup> edition of the Manual of Dietetic Practice is the first edition to refer to the dietary management of PCOS, focusing on weight management and a healthy balanced diet for women with PCOS (Thomas and Bishop, 2007). It should be noted that there are many women with PCOS who are lean, who despite having a normal BMI, may still be insulin resistant and display abdominal fat distribution (Herriot et al., 2008). Lean PCOS patients are also at increased disease risk (Dunaif et al., 1989) and suffer debilitating symptoms (Sheehan, 2004), and thus dietary management may also be of benefit to lean women with PCOS (Herriot et al., 2008). Dietary interventions to improve insulin resistance and reduce hyperinsulinaemia may be of greater benefit for short-term symptoms and long-term disease risk compared with weight loss alone. A number of review articles have been published proposing dietary management strategies that go beyond just weight loss (Marsh and Brand-Miller, 2005, Farshchi et al., 2007, Liepa et al., 2008). There is some evidence to show that by reducing the consumption of saturated fat (Galgani et al., 2008) and reducing the glycaemic index and glycaemic load (GI & GL) of the diet (McMillian-Price et al., 2006, Barclay et al., 2008), insulin sensitivity can be improved in insulin resistant populations, however there remains a paucity of studies in women with PCOS. In addition to dietary modifications, increasing physical activity has also been shown to improve insulin sensitivity in insulin resistant populations (Hayes and Kriska, 2008).

Increasing our understanding of the diets that women with PCOS choose to follow may help to focus the dietary issues that need to be addressed by dietitians when communicating appropriate nutritional advice to these women. Understanding where this patient group source their dietary information from, and the role of the dietitian in their current management, is essential in targeting dietetic resources, however, to date no survey of UK women with PCOS has been reported.

With weight management being promoted as the primary treatment within the literature and no published dietary guidelines or consensus statement for dietitians to follow, it is important to determine the dietary advice provided by dietitians. This information will help to inform future research in this area and the resources required to support dietitians working with women with PCOS.

This study aimed to determine the dietary advice is provided to women with PCOS by UK dietitians. The study also aimed to report the dietary information women with PCOS receive and from summarise the sources of information. A further aim was to determine how the dietary management of women with PCOS could be improved.

### **Methods:**

A questionnaire (Appendix 1), designed to assess the diet and lifestyle advice given to women with PCOS, was distributed to dietitians across the UK between November 2005 and February 2006. Dietitians were contacted via regional branches of the British Dietetic Association (BDA) either by post, email or in person at branch meetings. All BDA branches were contacted and only

dietitians who saw women with PCOS were requested to complete the questionnaire. Dietitians were also contacted by email via two BDA specialist groups; Diabetes Management and Education Group and Dietitians Working in Obesity Management UK, selected due to their relevance to the PCOS population. The number of questionnaires distributed was not recorded and thus response rate could not be calculated.

Women with PCOS were recruited via the UK charity for women whose lives are affected by PCOS (Verity). Of the 1138 women contacted via email, 206 women completed a patient questionnaire (Appendix 2) between May and November 2006, a response rate of 18%. Women were requested to state how their PCOS was diagnosed, 3 volunteers were excluded due to the absence of a clinical diagnosis. The patient questionnaire was designed specifically for the study and included questions relating to diagnosis, self reported symptoms, weight and height and any PCOS related nutritional advice received. A 7-day estimated food diary was completed by 196 women. The food diaries have previously been used in published studies although formal validation of the food diaries has not taken place. Information from the food diaries were entered into the dietary analysis software package Dietplan 6.3 (Forestfield software, UK) by a registered dietitian. Energy and macronutrient intake were calculated.

Ethical approval for the study was granted by Roehampton University Ethics Board. Frequencies and descriptive statistics were performed using SPSS version 15.0. A one sample ttest was used to compare nutrient intakes with the NDNS (2003) data for women aged 19-64 years. Significance reported when  $P < 0.05$ .

## **Results:**

### **Dietary advice from dietitians**

One hundred and five questionnaires were returned from a range of dietetic specialist areas including community dietetics (34%), general dietetics (26%), diabetes (22%) and obesity management (7%), the remaining 11% saw women with PCOS in other settings. The majority of dietitians who saw patients with PCOS were in GP surgeries or in the community, followed by general hospital clinic and endocrinology/ diabetes clinic setting. Approximately one-third of dietitians (36%) worked jointly with other healthcare professionals, ranging from liaising with diabetes specialist nurses to participating in a multidisciplinary team approach.

Twenty percent of the dietitians who responded saw at least one woman with PCOS a week and a further 24% saw 1-2 patients a month (the remaining 56% saw less than 1 patient a month). Dietitians reported receiving the majority of referrals from GP's (36%) endocrinology/ diabetes (31%) and fertility clinics (18%). There were a small number of PCOS specialist clinics within the UK accounting for 4% of the referrals to dietitians in this study.

The majority of dietitians reported providing advice to reduce energy intake (78%) and to choose lower glycaemic index foods (77%), often in combination. Forty nine percent recommended low fat, only 16% advocated reduced carbohydrate content and 3% advocated an increased protein intake. Other types of advice offered included regular meals, increased fibre and reduced saturated fat intake. All dietitians reported encouraging physical activity to women with PCOS.

Overall, only 24% (n=25) of dietitians reported seeing lean women with PCOS for dietary advice and of these only 3 dietitians saw lean patients regularly (more than once a month). Thus the majority of dietetics input is in overweight women with PCOS. Dietary advice given to lean women with PCOS focused predominately on reducing glycaemic index (n=24), healthy eating (n=9) and increasing physical activity (n=6).

Just 10% of dietitians reported having a departmental policy for the dietary management of PCOS.

Dietitians reported using a variety of sources to update their knowledge for practice in this area, predominantly journal articles (30%) and colleagues (22%). Other sources included conferences/meetings (19%) and the internet (11%), with 11% using the self help organisation Verity. Of the 34% of dietitians who reported feeling well informed of the literature, 64% believed that there was an insufficient evidence base for the dietary management of PCOS.

### **Characteristics of women with PCOS**

Women with PCOS (n=203) were most commonly diagnosed by their GP (38.5%) or gynaecologist (38.5%), with fewer women diagnosed by endocrinologists (8%), a combination of the above (14%) or dermatologists (1%). The mean (SD) age of women with PCOS was 32.5 (6.0) years (range 18-54 years), and 94% of volunteers self reported being Caucasian. The majority of women reported the classic presentation of symptoms as shown in table 1, 69% of the women reported having 3 or 4 of the symptoms.

The mean (SD) BMI of the women was 27.6 (7.5) kgm<sup>-2</sup> (range 16.6 – 52.1 kgm<sup>-2</sup>), calculated from the 196 who provided a self reported weight and height. Six women were underweight (BMI<18.5 kgm<sup>-2</sup>; 3%), 82 were within the healthy range (BMI 18.5-24.9 kgm<sup>-2</sup>; 42%) and 108 were overweight or obese (BMI >25 kgm<sup>-2</sup>; 55%). Just over half of the women (53%) reported their weight as being stable, 23% reported their weight was increasing, 13% reported their weight was decreasing and 9% reported their weight to be fluctuating (no data from 3 women).

### **Dietary advice followed by women with PCOS**

Fifty seven percent (n=113) of women reported to be following a diet specifically for their PCOS, including for weight loss. Data was available from 196 participants. Of those following a diet, 34% (n=38) of women reported to be following a low GI diet and 16% (n=18) a diet to reduce their body weight, including low fat diets, reduced portion sizes or membership of a commercial slimming club. An additional 26% (n=29) reported to be following a low GI diet in combination with another means of weight loss. The proportion of lean and overweight women following 'a diet' was similar as shown in Table 2.

Alterations in the consumption of specific foods, for example fruit or food containing wheat, as a way of managing their PCOS was reported by 11% of women (n=13 lean; n=6 overweight). Additionally, 36% of women reported taking a dietary or herbal supplement for their PCOS symptoms.

Total energy and nutrient intakes were significantly higher in the women with PCOS compared with women in the National Diet and Nutrition Survey (NDNS) (p<0.01) as shown in table 3 (Henderson et al., 2003). Percentage energy from carbohydrates was lower in women with PCOS compared with the NDNS (2003) values (p<0.01), and percentage energy from fat was significantly higher in women with PCOS. It is worth noting that the incidence of underreporting was high in the NDNS (2003) which might explain the differences found in total energy and macronutrient intake.

Nutritional information came from many sources, most commonly books, 22% of women with PCOS gained information from books. Only 15% (n=31) of women with PCOS reported having seen a dietitian for dietary advice, reducing to 3% with more than 2 appointments and 21% (n=44) had received dietary advice from a doctor. Overweight women were more likely to receive

dietary advice from a dietitian or doctor (21% and 25% respectively) than lean women (10% and 17% respectively).

When asked to rate the effect of diet or lifestyle modifications on their PCOS symptoms, 19% responded on the effect of weight loss and of those 74% reported improved symptoms. Thirty two percent reported on the effect of a low GI diet, 67% felt that it had improved their symptoms whilst 30% reported on the effect of nutrient/ herbal supplements, 56% felt that they had a beneficial effect. The modification perceived to be associated with the greatest improvement in symptoms was increasing physical activity; reported by 48% of women, 84% reported it improved symptoms.

### **Discussion:**

This is the first study of its kind to assess the extent and nature of advice provided by dietitians to women with PCOS, and therefore provides a useful insight into the service currently provided for this patient group. Likewise, this is the first survey investigating the dietary habits of UK women with PCOS, and findings will help to inform dietitians of the dietary practices of women with PCOS.

The average BMI of women studied was similar to a study of Italian women with PCOS (mean  $29.7 \text{ kgm}^{-2}$ ) with more than half classified as overweight or obese (Carmina et al., 2003). There is a substantial evidence base behind the reduced energy intake advice to promote weight loss and thus improvement in symptoms in overweight women with PCOS (Moran et al., 2003, Stamets et al., 2004, Qublan et al., 2007). Nearly three quarters (73%) of women classified as overweight or obese in this study were not following a diet to promote weight loss, this is of particular concern as weight loss has been shown to improve many of the symptoms of PCOS (Moran et al., 2003, Stamets et al., 2004, Qublan et al., 2007). A smaller study (n=35) also reported a high proportion (69%) of overweight women with PCOS were not following a weight reducing diet (Humphreys and Costarelli, 2008). This highlights a need to determine the reasons why a high proportion of overweight women with PCOS are not following a diet to promote weight loss. Considering the low number of women with PCOS who report seeing a dietitian they may be unaware of the importance of weight loss on symptom control and long term health.

Whilst altered glycaemic index diets remain popular for PCOS management, well controlled studies are needed to confirm the effectiveness of these approaches in both lean and overweight women with PCOS. In the current study dietitians' advice focused on a reduction in energy intake and a reduction in dietary GI, often in combination. A significant proportion of women with PCOS reported following a diet low in GI, of those over half reported beneficial effects. Low GI and GL diets have been shown to be beneficial for insulin resistance and acne in non PCOS study participants (Barclay et al., 2008, McMillian-Price et al., 2006, Smith et al., 2008). Herriot et al (2008) proposed benefits of a reduced GL diet on symptoms of PCOS in a retrospective audit of clinical practice, although this study did not control for medication use. Thus reducing the GI of the diet should continue to be advocated by dietitians to women with PCOS. In the current study, a proportion of dietitians advocated a reduced total fat diet, this is supported by two recent review articles which discuss the evidence for a link between saturated fat intake and insulin sensitivity (Galgani et al., 2008, Riserus, 2008).

On the surface women with PCOS appear to be following advice similar to that offered by dietitians, however, there are different approaches to low GI or weight loss diets that are not necessarily in line with healthy eating guidelines (Venn, 2007). The percentage energy from carbohydrates was reduced and percentage energy from fat increased in women with PCOS compared with the NDNS survey (Ruston, 2003). This may suggest that women were reducing the GL of their diet by reducing the quantity of carbohydrate and replacing the energy with fat.

However, as previously mentioned, increasing the fat content of the diet may have a detrimental impact on insulin sensitivity (Galgani et al., 2008, Riserus, 2008), therefore it is important that women have access to a dietitian to advise them on overall improvement in their dietary intake. Additionally further studies investigating the impact of low GI dietary interventions in lean women may increase the justification for dietitians to provide dietary advice to lean women with PCOS.

Women with PCOS reported following a range of alternative diets (such as low fruit, or excluding wheat) which do not have a rationale or evidence base and may put them at risk of excluding important nutrients in their diet. A high proportion of women with PCOS also reported taking nutrient or herbal supplements which many felt had a beneficial effect on their symptoms, although there is a paucity of studies investigating their potential benefits. It is important for dietitians to be aware of the alternative dietary approaches and various supplements used when providing dietary advice and help enable them to advise on the potential beneficial or harmful effects.

All dietitians surveyed advised women to increase their physical activity. This is in line with convincing research that physical activity improves insulin sensitivity (Assah et al., 2008, Snowling and Hopkins, 2006). Additionally, in the current study women with PCOS reported improved symptoms when they increased their level of physical activity. Despite such anecdotal evidence, studies investigating physical activity in women with PCOS are very limited. (Bruner et al., 2006) reports beneficial effects on insulin levels after 12 weeks of increased exercise in combination with nutritional therapy (n=7).

Women were recruited via the charity Verity and therefore are likely to have been exposed to the dietary information provided by the charity as part of its members' resources. The nutritional information includes healthy eating advice as well as non conventional/ alternative advice, which may provide some explanation for the 'other' diets followed by participants. All women with PCOS in the current study were members of Verity and thus were a self selected group who had joined a support group.

Nutritional information came from many sources, most commonly books, with only 15% of women having seen a dietitian. At the time of the study there was very little literature publically available on diet and PCOS written by dietitians, since 2007 the quality of information has improved with two books authored by dietitians (Elsheikh and Murphy, 2008, Bussell, 2007) and the Food Facts Sheet on the British Dietetic website (Bailey et al., 2007). The predominant use of books as a source of information is in contrast to a small study of Australian women with PCOS who preferentially used the internet (Avery and Braunack-Mayer, 2007).

It is a concern that very few women saw dietitians for dietary advice, this is in agreement with findings by Humphreys and Costarelli (2008) who interviewed 53 women with PCOS in a London Hospital, the reasons for this are beyond the scope of this study. However, knowing why women are either not being referred or are choosing not to see dietitians is of great importance. In addition to the potential short term benefits of diet and lifestyle modifications for symptom control, women with PCOS are also an important population group for health promotion, with appropriate dietary interventions having the potential to impact upon future diabetes and CVD development within this group (Diabetes Prevention Program Research Group, 2002).

Since the study was carried out there have been increases in the number of publications available to dietitians and women with PCOS. However, the evidence base for clinical guidelines remains inadequate, with little progress since a review of the evidence for dietary management in women

with PCOS by Marsh and Brand-Miller in 2005. Dietitians gained information from a variety of sources, predominately journal articles and colleagues. However, since this survey PCOS UK has been established ([www.pcos-uk.org.uk](http://www.pcos-uk.org.uk)), providing resources and increasing awareness of PCOS amongst healthcare professionals. The lack of consensus is reflected in the number of dietitians not feeling adequately informed, with very few departmental policies and the variability in the advice offered. Dietary management of women with PCOS could be improved by a consensus statement of evidence based dietary advice for lean and overweight women with PCOS. Additionally, women with PCOS are consulted in a variety of clinical settings with very few specialist clinics, or specialist dietitians. This may impact on the quality of advice women with PCOS are receiving from dietitians.

PCOS is a common disorder and dietitians should be aware of the condition and the possible dietary management approaches. Dietary intervention studies investigating the effect of reduced glycaemic index diets on symptom control and disease risk profile in women with PCOS are long overdue. This study confirms that, although women with PCOS recognise the importance of diet and lifestyle factors dietary information is often obtained from non dietetic sources which may be inappropriate and there is a clear role for dietitians in ensuring optimum management of this patient group. A consensus statement of evidence based dietary advice for lean and overweight women with PCOS is needed and would be a useful resource for dietitians.

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Table 1. Self reported symptoms of women with PCOS (n=203)

Symptom reported	Number of women reporting the symptom (%)
Over weight	148 (73)
Hirsutism	165 (80)
Acne	119 (58)
Irregular menstrual cycle	155 (75)

Table 2. Number of underweight, lean and overweight women with PCOS following a specific diet to manage their PCOS symptoms (n=196).

	Number (%) of women with PCOS		
	Underweight BMI < 18.5 kgm <sup>-2</sup>	Lean BMI 18.5-24.9 kgm <sup>-2</sup>	Overweight BMI >25 kgm <sup>-2</sup>
No diet	3 (50)	33 (40)	47 (44)
GI	1 (16.5)	17 (21)	20 (18)
Wt loss	0	7 (9)	11 (10)
GI & wt loss	1 (16.5)	10 (12)	18 (17)
Other diet*	1(16.5)	15 (18)	12 (11)

\* Includes alteration to carbohydrate or protein intake and exclusion of specific food groups. No BMI data for 7 participants.

Table 3. Mean (SD) nutrient intake of women with PCOS (n=196)

		Mean (SD)	NDNS
		Energy	KJ
	kcal	1993 (435)	1629 (418)
Fat	g	85 (27)	61 (22)
	%E	38 (7)	35 (7)
Saturated Fat	g	36 (9)	23 (10)
	%E	12 (3)	13 (3)
Protein	g	78 (18)	64 (17)
	%E	16 (4)	15 (4)
Carbohydrate	g	229 (59)	203 (59)
	%E	43 (7)	49 (7)

NDNS: National Diet and Nutrition Survey (Ruston et al 2003)  
Data from women aged 19-64 years. %E: percentage of energy intake.  
Significant difference in all values (p<0.01) one sample ttest