

University of Derby

The impact of Polycystic Ovary Syndrome (PCOS)
on quality of life: exploration, measurement and
intervention.

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List of Abbreviations

PCOS	Polycystic Ovary Syndrome
NIH	National Institute of Health
ESHRE/ASRM	European Society of Human Reproduction and Embryology/American Society for Reproductive Medicine
PCO	Polycystic Ovary
ROT	Rotterdam Criteria
AES	Androgen Excess Society
IR	Insulin Resistance
OCP	Oral Contraceptive Pill
CC	Clomiphene Citrate (Clomid)
HRQoL	Health Related Quality of Life
BMI	Body Mass Index
RCT	Randomised Controlled Trial
OPPI	Online Positive Psychology Intervention
QoL	Quality of Life
CBT	Cognitive Behavioural Therapy

Measures

PCOSQ	Polycystic Ovary Syndrome Questionnaire
PCOS QOL	Polycystic Ovary Syndrome Quality of Life
HADS	Hospital Anxiety and Depression Scale
WHOQOL BREF	World Health Organisation Quality of Life Brief

Preface

This thesis submitted for the degree of Doctor of Philosophy entitled “The impact of Polycystic Ovary Syndrome (PCOS) on quality of life: exploration, measurement and intervention” is based on work conducted by the author at The University of Derby between the years 2011 and 2015.

All the work recorded in this thesis is original unless otherwise acknowledged in the text or by references. If necessary, for the deposit of this thesis in the institutional repository, permission to disseminate third party material has been sought and granted by copyright holders. None of the work has been submitted for another degree in this or any other University.

Dissemination

The contents of this thesis have been published in *The Journal of Health Psychology*, presented at various conferences both nationally and internationally and also presented by invitation.

Publications

Williams, S., Sheffield, D., & Knibb, R. (2015). 'Everything's from the inside out with PCOS': Exploring women's experiences of living with polycystic ovary syndrome and co-morbidities through Skype™ interviews. *Health Psychology Open*. doi: 10.1177/2055102915603051

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Media

Newspaper

Jones, C. (2014, August 21). *Derby student to have pioneering work on ovary problem published in top journal*. The Derby Telegraph. Derby: The Derby Telegraph.

Radio

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Abstract

Polycystic Ovary Syndrome (PCOS) is one of the most common endocrine disorders amongst women, estimated to affect one out of 10 women. Symptoms include infertility, obesity, alopecia, acne, hirsutism and menstrual irregularities. Women with the syndrome are also more likely to experience co-morbid physical and psychological conditions such as diabetes, heart disease, endometrial cancer and also depression and anxiety. PCOS has also been found to have a negative impact on quality of life.

This thesis aimed to further understanding, and improve quality of life of women with PCOS in the UK. To achieve this, the thesis aimed to investigate and identify how women with PCOS in the UK perceive and define their quality of life and to further understanding of the day-to-day experience of living with PCOS. Moreover, in order to measure quality of life, it aimed to develop and validate a UK disease-specific quality of life measure for women with PCOS. It also aimed to identify, develop and test a pilot intervention to increase quality of life in women with PCOS. To achieve these aims a mixed-methods approach was taken employing a variety of data generation and collection methods including: photovoice, online Skype™ interviews; LimeSurvey and Qualtrics.

The findings of this thesis emphasise that PCOS has a negative impact on quality of life; encompassing psychological, social, environmental, and physical domains of quality of life. Women with PCOS who experienced the symptoms of infertility, hirsutism, weight, alopecia, skin discolouration, skin tags and mood swings had significantly lower scores of overall quality of life than those women who did not experience the symptoms. In addition, those women with PCOS who had a diagnosis of anxiety and/or depression had reduced quality of life.

The dissemination of these findings will enable health care professionals to better understand the experience of living with PCOS and its impact on quality of life. Moreover, this thesis identifies many areas for future research which will enable a better understanding of the impact of PCOS on quality of life. Finally, this thesis makes recommendations for clinical practice which include improvement of support from health care professionals for women with PCOS in order to help them better manage their symptoms, and therefore improve their overall quality of life.

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Chapter One -Polycystic Ovary Syndrome: An introduction.

1.1 Introduction

This chapter introduces Polycystic Ovary Syndrome (PCOS) and details the symptoms, treatments and diagnostic definitions of PCOS. It then discusses PCOS as a long-term condition and women's health. Coping in long-term conditions is detailed with a focus on management of long-term conditions. Next, quality of life is discussed in order to set a context for a following discussion of what is currently known about the impact of PCOS on quality of life. This chapter then concludes with the overarching, and specific aims of this thesis.

1.2 Long-term Conditions

Radley (2004) suggests that when diagnosed with long-term illness, a person changes from being healthy, to living with long-term illness in a world of health. Almost half of the UK population has reported having a long-standing illness (46.6%) with some of the most common long-term conditions in the UK being hypertension, asthma and depression (ONS, 2015). The Department of Health (DOH, 2015) state that in England alone, more than 15 million people have a long-term condition. It is also suggested that the number of individuals with multiple long-term conditions is set to rise to 2.9 million in 2018 (DOH, 2012). Moreover, the cost of care for people with long-term conditions in England accounts for 70% of the monies spent on health and social care (DOH, 2015), suggesting that long-term conditions are a large cost to the economy. As such, research exploring long-term, or long-term conditions, is necessary to help further understanding of long-term conditions and their impact.

De Ridder (2004) defines long-term illness as a disorder which persists for an extended period of time which is incurable. Moreover, she suggests that most long-term conditions get progressively worse over time. Similarly, Forshaw (2002) suggests that long-term illness is not something that can be easily cured but is a long lasting, and often permanent condition which becomes part of a person's life. Holman and Lorig (1992) argue that there are many components to long-term illness and these can interact to worsen, or to lessen, the illness effect. They suggest that whilst there may be biological differences in long-term illness, the illness components and their interactions have similarities (Holman & Lorig, 1992). However, not all long-term conditions are

the same; some may be life threatening such as cancer or heart disease, and others are considered not to be, such as psoriasis (Radley, 2004).

It is of note that within the literature the term chronic conditions and long-term conditions are often used interchangeably (e.g., Barlow, Singh, Bayer & Curry, 2007). However, the UK Government (DOH, 2015) and the UK National Health Service (NHS; 2016) both utilise the terminology, long-term condition. As such, this thesis shall refer to long-term conditions throughout.

1.3 Polycystic Ovary Syndrome

PCOS is a long-term condition which manifests across the lifespan (Teede, Deeks & Moran, 2010). It was first defined in 1935 by Stein and Leventhal as Stein-Leventhal syndrome and is considered as the most common endocrine disorder amongst women of reproductive age (Franks, 1995; McGowan, 2011) affecting approximately 6.5% of women (Asuncion et al., 2000; Azziz et al., 2004). The pathogenesis of PCOS is poorly understood (Goodarzi & Azziz, 2006; Ong, Theodoru & Ledger, 2006). Indeed, Franks, McCarthy and Hardy (2006) suggest that although the aetiology of PCOS remains uncertain, there is increasing evidence for a genetic basis: they propose that the genesis of the syndrome may be during early development, perhaps in utero. However, de Melo et al. (2015) report that whilst PCOS might have its origin in utero, interaction between genetic and environmental factors is crucial for its appearance.

1.3.1 Symptoms

Symptoms of PCOS, or Polycystic Ovarian Syndrome, can include insulin resistance, obesity (Goudas & Dumesic, 1997), acne (Coffey, Bano & Mason, 2006) hair loss and infertility (Elsenbruch et al., 2003). Specifically, women with PCOS may experience anovulatory infertility which is infertility due to lack of ovulation (Franks, Stark & Hardy, 2008). PCOS is the most common cause of anovulatory infertility in women (Balen & Rutherford, 2007; Gorry, White & Franks, 2006). In addition, women with PCOS can experience hirsutism, which can occur as a result of hyperandrogenism (excess levels of androgens; Oláh, 2004) and is defined in women as excessive facial and/or body hair in a male like distribution (Archer & Chang, 2004).

1.3.2 Treatment

Treatment of PCOS has developed over the years but as the cause of PCOS is not clearly defined, the treatment of PCOS is symptomatic (Rosenfield, 2008). Common treatments include the oral contraceptive pill (Teede, Hutchinson, Zoungas & Meyer, 2006), metformin (Herriot, Whitcroft & Jeanes, 2008; La Marca, Artensio, Stabile & Volpe, 2005) and clomiphene citrate (Hill, 2003). Lifestyle changes, including weight loss and dietary changes, are also commonly prescribed and advised for women with PCOS (Ehrmann, 2002; Harris-Glocker, Davidson, Kochman, Guzick & Hoeger, 2010; Hart & Norman, 2006; Norman, Davies, Lord & Moran, 2002; Pasquali, Gambineri, & Pagotto, 2006; Teede et al., 2006; Thomson et al., 2010). The focus, therefore, has been on treating symptoms, with less literature exploring the experience of living with these symptoms and their impact on quality of life.

1.3.3 Diagnostic Definition

The definition of PCOS has been disputed since its conception in 1935 (Stein & Leventhal) and debate over an accepted definition is still rife. Consequently, comparative research on PCOS has been hampered by the absence of a consensus on the definition of PCOS (Ong et al., 2006).

There are currently three widely used PCOS diagnostic criteria. The 1990 National Institute of Health (NIH) criteria (cf. NIH, 2012), which requires only the presence of chronic anovulation and clinical or biochemical signs of hyperandrogenism (excess levels of androgens), and not polycystic ovaries. The Androgen Excess Society (AES) criteria suggests that the NIH criteria should be accepted, however, with modifications whereby women with oligomenorrhea (light or infrequent menstrual cycles) and polycystic ovaries, but no hyperandrogenism should not be considered to have PCOS (Azziz et al., 2006). The final diagnostic criteria are the 2003 Rotterdam Criteria (2004) which require two of the following three symptoms: oligo and/or anovulation, clinical and/or biochemical signs of hyperandrogenism, polycystic ovaries. The Rotterdam criteria, therefore, recognise four phenotypes of PCOS (Norman, Dewailly, Legro & Hickey, 2007): Severe PCOS (all diagnostic criteria met), Hyperandrogenism and anovulation, Ovulatory PCOS (polycystic ovaries and hyperandrogenism) and Mild PCOS (anovulation and polycystic ovaries). The Rotterdam criteria are therefore more inclusive than the NIH or AES (Norman et al.).

In 1960, Roberts and Haines claimed that PCOS was not a well-defined entity. More than 40 years later it was suggested that the need for a universal diagnostic criteria remained to be implemented by researchers and health care professionals (Brady, Mousa & Mousa, 2009). Indeed, Amato, Galluzzo, Finocchiaro, Criscimanna and Giordano (2008) conducted a retrospective study on patients suspected of PCOS (N=204) and a control group (N=34) in the authors' outpatient clinic to assess whether the application of the three diagnostic criteria differentially characterised women with PCOS. They found that the prevalence of PCOS in the women according to the NIH criteria was 51%, 83% according to the Rotterdam criteria and 71% according to the AES. Correspondingly, in 2013 a NIH panel recommended that diagnosis of PCOS should be made according to the 'broad, inclusionary Rotterdam criteria', however, to date research still predominately fails to detail the diagnostic criteria used to diagnose participants with PCOS. Moreover, there is no way of ensuring that clinicians implement the Rotterdam Criteria (2004) as the primary diagnostic criteria. As such, there remains a lack of consistency in diagnostic criteria utilised in practice, and reported in research (Lujan, Chizen & Pierson, 2008). Therefore, in order to be broad and inclusive, the inclusion criteria for this thesis will be a sample of women with a self-reported diagnosis of PCOS; with no exclusions on the basis of the criteria by which they were diagnosed.

1.4 PCOS as a long-term condition

Marks et al. (2005) suggest long-term conditions are usually characterised by depression, anxiety, fatigue, pain, and limits on normal day-to-day activities. Similarly, the DOH (2015) suggest that long-term conditions can impact all aspects of an individual's life from their ability to work, to their social relationships. PCOS embodies many of these characteristics including an impact on the individual's ability to take part in normal day-to-day activities (Brady et al., 2009) and fatigue (Dokras, 2012). Women with PCOS are also likely to experience depression and anxiety which can be characteristic of long-term conditions (Marks et al., 2005). Indeed, women with PCOS experience increased levels of anxiety and depression in comparison to women without PCOS (Deeks, Gibson-Helm, Paul & Teede, 2011). In a sample of 448 women with PCOS, Benson et al. (2009) found that 34% demonstrated elevated levels of anxiety and 20.5% demonstrated elevated levels of depression when measured with the Hospital Anxiety and Depression Scale (HADS; Zigmond & Snaith, 1983). They also suggested that co-morbid

anxiety and depression is common in women with PCOS. Similarly, Kerchner, Lester, Stuart and Dokras (2009) found a 35% prevalence rate of depression in women with PCOS and only 10% in controls. However, it has been suggested that the psychological implications of PCOS are easily underestimated and have been largely ignored (McCook, Reame & Thatcher, 2005).

Women with PCOS are also likely to experience other comorbid conditions including cardiovascular disease, type two diabetes mellitus and endometrial cancer (Chittenden, Fullerton, Maheshwari & Bhattacharya, 2009; Fearnley et al., 2010; Navaratnarajah, Pillay & Hardiman, 2008). Gottschau, Kjaer, Jensen, Munk and Mellemkjaer (2015) whilst supporting findings of an increased risk of endometrial cancer in PCOS, also suggested that women with PCOS were at increased risk of kidney, colon and brain cancers.

1.5 Women's Health

Women can experience long-term conditions which are gender specific, including: endometriosis and cancers, including breast cancer and carrying of the BRCA gene (NHS, 2014; Ogden, 2012). Similarly to PCOS, experiencing endometriosis and carrying of the BRCA 1 or 2 gene can both impact women and their fertility (Facchin et al., 2015; Donnelly et al., 2013). They have also been found to have a negative impact on quality of life (Finch & Narod, 2011; Friedl et al., 2015). Women may also experience issues concerning fertility including miscarriages, infertility and menopause (Ogden) which also impair quality of life in women (Chachamovich et al., 2010).

Endometriosis is a condition which affects women of reproductive age which has been shown to reduce quality of life in those women that experience it (Facchin et al., 2015; Friedl et al., 2015). Women with endometriosis have also been found to experience depression and anxiety in addition to their endometriosis (Friedl et al., 2015; Sepulcri & Amaral, 2009). Symptoms of endometriosis can include infertility or subfertility (Mavrelou & Saridogan, 2015). There is no cure for endometriosis and treatment is symptomatic, often treatment is in response to fertility issues, however the condition can improve over time in some cases (NHS, 2015). As such endometriosis is similar to PCOS as there is no known cure, it impacts women of reproductive age, treatment is symptomatic and can include similar treatments (for example, the oral

contraceptive pill). In addition, women with endometriosis can experience a negative impact on their fertility, as can women with PCOS.

Women are also at risk of carrying the BRCA 1 or 2 gene mutation which increases the carrier's risk of developing breast or ovarian cancer during their lifetime, more so than women in the general population (Donnelly et al., 2013; Smith, Hanson, Mineau & Buys, 2012). Whilst carrying the BRCA gene may not be considered a long-term condition in the way that PCOS and Endometriosis are, carrying the gene can have an impact on an individual's fertility, including their family planning (Donnelly et al.; Friedman & Kramer, 2005; Werner-Lin, 2010). Women who carry the BRCA genes must make a decision with regards to their family planning as pregnancy is associated with an increased risk of developing cancer (Friedman & Kramer, 2005) and it is also possible that any child may inherit the gene (Werner-Lin, 2008). Certainly, Werner-Lin (2008) found that women with the gene felt a 'sense of urgency' (p.428) to have children before preventative surgeries, or disease progression, remove this option for them. Other participants in Werner-Lin's study faced a decision of whether or not to have children and risk passing the gene on to them. There are, therefore, similarities with PCOS whereby women with the BRCA gene may experience sub- and infertility.

The NHS define someone as infertile if they have never conceived a child in the past and they have difficulty conceiving (2014). As detailed, women with PCOS may experience problems with regards to their fertility (Legro et al., 2007). In addition, women with endometriosis (Facchin et al., 2015) and women who have undergone chemotherapy for treatment of cancer (Bedoschi, Navarro & Oktay, 2016) may also experience infertility. Whilst men can also experience infertility either due to biological causes or due to the experience as part of a couple (NHS, 2014), the ability to carry a child during pregnancy is unique to women. Greil, Slauson-Blevins and McQuillan (2010) suggest that infertility is associated with psychological distress due to the individual's inability to meet a desired social goal (that of having children). Moreover, infertility has been found to have a negative impact on quality of life particularly for women, with lower quality of life scores in women than men (Chachamovich et al., 2010).

1.6 Coping in long-term conditions

To date there is little research which explores coping in women with PCOS. Carron and Alvero (2014) report that women with PCOS who were experiencing psychological distress were more likely to use maladaptive coping strategies. Moreover, Özenli et al. (2009) found that women with PCOS in Turkey were more likely to use passive, emotion-focused coping strategies in comparison to controls. As such, the research which is available suggests that women with PCOS may use maladaptive coping strategies, which are associated with decreased quality of life in women with PCOS (Benson et al., 2010).

Friedman (2002) suggests that there are several types of coping that people use when faced with a long-term illness. The first coping technique involves denying or minimising the seriousness of the condition, this is colloquially known as a defence mechanism. The second coping technique Friedman suggests is information seeking whereby an individual gathers information about a condition in order to gain a sense of control. Thirdly, Friedman suggests that support or requests for reassurance form a coping technique, whereby individuals gain comfort from others. Goal setting and visualisation of possible outcomes form the fourth and fifth techniques employed by people with a long-term condition. Finally, Friedman suggests that people search for meaning as a coping technique. Radley (2004), similarly, details two types of coping mechanisms: emotion-based coping, an attempt to minimise the emotional impact of a condition through the adoption of a specific attitude, and problem-based coping whereby an individual tries to do something about any difficulties they experience, therefore controlling them. De Ridder (2004) suggests that controllability of a disease is a key factor influencing how individuals experience long-term conditions. For example some conditions, such as diabetes, are controllable by self-care routines (such as using diet and medication), thus increasing perceived control. However, De Ridder argues that self-care routines may impose a burden on the individuals, due to the responsibility to take care of their illness; their daily lives are filled with performing tasks related to illness management. Alternatively, individuals may experience uncontrollable diseases, such as multiple sclerosis, which could result in feelings of helplessness (Fournier, de Ridder & Bensing, 2002). Interestingly, Helgeson (1992) suggests that perceived control is a stronger predictor of adjustment to long-term illness than actual control.

Clark et al. (1991) define self-management as the “day to day tasks an individual must undertake to control or reduce the impact of disease on physical health status” (p.5). Research suggests that in long-term illness, the responsibility for the day-to-day management of a condition may gradually shift from the health care professionals to the individual (Barlow, Wright, Sheasby, Turner & Hainsworth, 2002). Clark et al. propose that successful self-management of long-term conditions requires the individual to have a sufficient amount of knowledge of the condition and performance of the activities needed for condition management to maintain adequate psychosocial functioning. In managing PCOS, research suggests that women with PCOS often feel frustrated with the information provided by their health care professional and as such, use alternative sources of information to increase their knowledge of PCOS (Crete & Adamshick, 2011; Snyder, 2006; Weiss & Bulmer, 2011).

Leventhal, Brisette and Leventhal (2003) suggest that the procedures used by an individual to control ongoing illness threats range from the use of dietary supplements, prescribed medications or over the counter medications and prescribed treatments, as well as treatments suggested by friends and acquaintances over the internet. Similarly, women with PCOS attempt to control their symptoms, through use of hair removal methods (Kitzinger & Willmott, 2002; Snyder, 2006), self-treatment methods (Crete & Adamshick, 2011) and adjustments to diet and physical activity (Weiss & Bulmer, 2011). They have also been evidenced to use the internet for treatment related advice (Holbrey & Coulson, 2013).

Clark et al. (1991) suggest that individuals with long-term illness also have to cope with the psychosocial problems generated by their long-term disease and must, therefore, manage their daily living according to their financial and social conditions. Similarly, Holroyd and Creer (1986) suggest that self-management means having, or being able to obtain, the skills and resources necessary to best accommodate to the long-term condition. However, Barlow et al. (2002) claim that there is no ‘gold standard’ definition of self-management and propose that self-management refers to the “individuals ability to manage the symptoms, treatment, physical and psychosocial consequences and lifestyle changes inherent in living with long-term conditions” (p.178). Both definitions, however, refer to how an individual manages their life, and consequent changes, when dealing with a long-term condition.

Barlow et al. (2002) suggest that efficacious self-management encompasses the individual's ability to monitor their condition and to influence the cognitive, behavioural and emotional responses necessary to maintain a satisfactory quality of life: therefore, a dynamic and continuous process of self-regulation is established. Clark, Gong and Kaciroti (2014) similarly state that to be self-regulating one must be observant and make judgements based on that observation. They suggest that management strategies must evolve from the person's observations, judgements and reactions whilst considering the internal and external factors. However, as the intensity of long-term disease can fluctuate between periods of greater and lesser severity and on a day-to-day basis (Holman & Lorig, 1992) this may make self-regulation difficult for individuals with long-term conditions. In addition, if a treatment has a negative or adverse impact on the individual, then an additional problem may be created (Horman & Lorig, 1992). This is similar to PCOS, whereby the condition and its management may change over time (Sheehan, 2004).

Self-regulation theory proposes that individuals will use strategies based on their understanding of the experience, therefore as their perceptions of their condition change, so too will their management strategies (Petrie, Broadbent & Meechan, 2003). Indeed, there are many models of self-regulation (Carver & Scheier, 2000; Lazarus & Folkman, 1987; Leventhal et al., 1984), however they all interpret self-regulation as a systematic process (Cameron & Leventhal, 2003). Clark et al. (2014) propose a model of disease management where self-regulation is considered key to achieving the individual's goal. This model involves management strategies whereby the individual aims to keep the condition under control. Clark et al. (2011) also suggest that their model of disease management is based on the idea that through self-regulatory processes individuals learn the strategies they use to manage their condition.

The Common Sense Model of self-regulation (Leventhal et al., 1984), also known as Leventhal's self-regulatory model of illness cognition and behaviour (Cameron & Moss-Morris, 2004) is one such model which can be applied to health and illness specifically. Leventhal's self-regulatory model of illness behaviour suggests that people deal with their illness symptoms in the same way as they would other problems, and so attempt to solve the problem and return to normality

(Ogden, 2012). There are three key stages in Leventhal's model, these include: interpretation, coping and appraisal. Within the interpretation stage, there are five dimensions of illness representation which need to be interpreted by the individual: identity (the illness label or diagnosis), cause (the factors believed to have caused the illness), timeline (expected duration of illness), consequences (effects of the illness: physical, social and psychological) and control/cure (the extent to which the illness can be cured or controlled) (Cameron & Moss-Morris, 2004). These three stages, interpretation, coping and appraisal, inter-relate in a dynamic way, consequently maintaining normality, or in other words regulating the self (Ogden).

Barlow et al. (2002) suggest that self-management approaches are made up of several components including: information, drug and symptom management, management of psychological consequences of the long-term condition, life style, social support and communication; although these categories are not mutually exclusive. In addition, they argue that disease specific management approaches focus on medication and symptom management and, whilst there are many similarities between self-management approaches across long-term conditions, there are also differences. Similarly, Holman and Lorig (1992) suggest that there are seven areas of skill needed for an individual to manage their conditions, including: minimising or overcoming physical debility, establishing realistic expectations and responses to the variations of the illness, interpreting and managing symptoms, learning how to judge the effects of medications and manage their use, becoming adept at problem solving, communicating with health care professionals and using community resources.

Self-management may be a means of bridging the gap between patients' needs and the capacity of health services to meet those needs (Barlow et al., 2002). However, there is a need for health professionals to be trained to ensure that patients self-management abilities are maintained and fostered in clinical settings (Barlow et al., 2002). Clark et al. (2011) suggest that the day-to-day manager of disease is the patient who undertakes the actions with the guidance of the clinician. They further propose that self-management strategies comprise of the individual's means to keep the disease and its effects under control and that these strategies may be consistent, or not consistent, with the clinician's recommendations. Similarly, Holman and Lorig (1992) propose that it is the role of the individual with the condition to engage in maximum feasible self-

management, whilst it is the healthcare professional's role to develop and facilitate the individual's self-management and to provide expert knowledge. In long-term conditions, the patient often becomes the most knowledgeable person concerning the consequences of the disease. Therefore, appropriate management of long-term disease requires the development of a partnership between the health care professional and the individual (Holman & Lorig, 1992).

Whilst there is some evidence that women with PCOS utilise self-management and self-regulation strategies (Bates & Legro, 2013; Deeks, Gibson-Helm, Paul & Teede, 2011; Kitzinger & Willmott, 2002; Percy, Gibbs, Potter & Boardman, 2009; Snyder, 2006), there is little research exploring how women with PCOS experience this management and their condition on a day-to-day basis, or how it impacts on their quality of life.

1.7 Quality of Life

Health-related quality of life of patients with long-term conditions is frequently impaired (Sprangers et al., 2000). De Ridder (2004) suggests that long-term illness has the ability to induce changes in an individual's life which can, consequently, have negative effects on their quality of life. Accordingly, there is an expansive literature exploring health-related quality of life in individuals with long-term conditions, including: breast cancer (Ganz et al., 2002), chronic heart failure (Beladinelli, Georgiou, Cianci & Purcaro, 1999), Cushing's disease (Heald et al., 2004; van Aken et al., 2005), chronic obstructive pulmonary disease (Gore, Brothy & Greenstone, 2000; Seemungal et al., 1998), inflammatory bowel disease (Simrén et al., 2002), Celiac disease (van Koppen et al., 2009) and endometriosis (Nnoaham et al., 2011; Simoens et al., 2012).

Research has shown that PCOS is related to poor quality of life (Elsenbruch et al., 2003; McCook et al., 2005; Hahn et al., 2005) and it is therefore important to consider quality of life in relation to long-term conditions and to PCOS specifically. Recent research exploring coping, quality of life and PCOS suggests that coping strategies correlate with quality of life in women with PCOS (Kolahi et al. 2015). Strategies that relate to better quality of life include cognitive (acceptance), problem solving (actively dealing with the problem), social support and emotional strategies (seeking social and emotional support). In addition, Benson et al. (2010) found that in

women with PCOS; passive, or maladaptive coping, was associated with greater anxiety, depression and reduced quality of life. Indeed, Banyard (1997) proposes that the aim for any treatment for long-term illness is to improve the patient's quality of life.

1.7.1 Defining Quality of Life

What determines quality of life has been considered in scientific investigation for many years (Power, Bullinger, Harper & the WHOQOL group, 1999). Power et al. suggest that quality of life as a concept came at a time when classic medical endpoints, such as mortality and morbidity, were criticised for failing to adequately represent potential outcomes of medical interventions. The World Health Organization (WHO) define quality of life as “an individual's perception of their position in life in the context of the culture and value systems in which they live, and in relation to their goals, expectations, standards and concerns. It is a broad ranging concept affected in a complex way by the person's physical health, psychological state, level of independence, social relationships, their relationship to the salient features of their environment and their spiritual, religious and personal beliefs” (WHOQOL Group, 1994, p.1).

The WHOQOL group specify that there are six domains of quality of life (see WHOQOL Group, 1994, p.4), including: physical health (energy and fatigue, pain and discomfort, sleep and rest); psychological health (bodily image and appearance, negative feelings, positive feelings, self-esteem and thinking, learning, memory and concentration); level of independence (mobility, activities of daily living, dependence on medical substances and aids, work capacity); social relationships (personal relationships, social support and sexual activity); environment (financial resources, freedom, physical safety and security, health and social care, home environment, opportunities for acquiring new information and skills; participation in and opportunities for recreation, physical environment and transport); and spirituality/religion/personal beliefs. Fallowfield (1990) defined quality of life as having four dimensions: psychological (mood, emotional distress, adjustment to illness), social (relationships, social and leisure activities), occupational (paid and unpaid work) and physical (mobility, pain, sleep and appetite), reflecting the psychological, physical and social domains of the WHOQOL definition (1994).

Orley, Saxena and Herrman (1998) suggest that the emphasis within the WHOQOL definition is the subjective nature of quality of life and the need to explore aspects of life that the individual considers to have an impact on their quality of life. Moreover, they suggest that quality of life is an internal, subjective experience coloured by the individual's personality, expectations, early experiences and mental state. Skevington (2002) similarly suggests that quality of life is about the meaning people derive from the important aspects of their life. Quality of life, therefore, is dependent on the person's perceptions of what is important and their subjective experience.

Health-related quality of life has been proposed as a related construct and sub-domain of quality of life (Learmonth, Alwick, McAuley & Motl, 2015). Power et al. (1999) propose that the concept of health-related quality of life is a patient-perceived multidimensional construct. Moreover, Muldoon, Barger, Flory and Manuck (1998) suggest that health-related quality of life moves beyond manifestations of a condition to the impact of the condition on everyday life. Indeed, Bowling (1995, 2001) suggests that health is one of the most important areas of quality of life nominated by individuals and therefore, health-related quality of life should be included as a dimension within quality of life. However, Bowling (2001) reports that quality of life is often referred to as health-related quality of life in research.

Health-related quality of life is defined by Testa and Simonson (1996) as the physical, psychological and social domains of health that are influenced by a person's experiences, beliefs, expectations and perceptions. More recently, Carr, Gibson and Robinson (2001, p.1240) defined health-related quality of life as "those aspects of an individual's subjective experience that relate both directly and indirectly to health, disease, disability and impairment". Moreover, they suggest that quality of life is a broad concept concerned with whether disease or impairment limits a person's ability to fulfil a normal role. Quality of life, therefore, appears to be an assortment of interactive and subjective domains (Lawton, 1991). As such, whilst there are many differing definitions of quality of life there are arguably similarities within the underlying constructs, including; the individual's perspective, their goals and expectations, their psychological health, and physical and social domains of quality of life.

Despite this number of broadly similar definitions, Fayers and Machin (2007) suggest that quality of life is a poorly defined term. Moreover, they suggest that quality of life can mean different things to different people. As such, health-related quality of life, whilst still being a loose definition, can include factors such as; general health, physical symptoms, physical and emotional functioning and social well-being. Consequently, this thesis utilises a broad definition of quality of life which encompasses the physical, psychological and social domains of health that are influenced by a person's experiences, beliefs, expectations and perceptions (Testa & Simonson, 1996; WHOQOL Group, 1994) and also considers the symptoms and side effects of the disease that may affect quality of life (Fayers & Machin).

1.7.2 Measuring Quality of Life

Rapley (2003) suggests that there is variability in the definition of quality of life, however, they maintain that quality of life is a multi-dimensional construct. Bowling (2001) similarly suggests that quality of life is a vague, but multidimensional concept which incorporates all aspects of an individual's life. As such, measures of quality of life should include a number of dimensions and include several concepts (Fayers & Machin, 2001).

There are various ways of measuring quality of life including; asking the patient or using standardised quality of life assessment instruments, which can be both disease-specific and generic (Fayers & Machin, 2007). In 1994 The WHOQOL group developed the WHOQOL-100 scale, an international health-related, multi-dimensional quality of life measure. The core domains include a physical and a psychology domain, in addition to: level of independence, social relationships and environment. An additional culture specific domain, spirituality/religion/personal beliefs, was included for those cultures and countries where it was felt appropriate, such as Thailand (WHOQOL Group, 1994). This is in line with suggestions by Fayers and Machin (2001) that most instruments intended for health status include at least some items that focus on physical, emotional and social functioning. Similarly, Muldoon et al. (1998) suggest that quality of life questionnaires generally embody quality of life as an individual's level of functioning or perceived health status or wellbeing.

Further development of the WHOQOL-100 scale led to the validation of a reduced item version called the WHOQOL- BREF (Skevington, Lofty & O'Connell, 2004). This scale identified similar domains of physical health, psychological issues, social relationships and environment. Cruz, Comey, Fleck and Polyanczyk (2009) however, argue that the WHOQOL-BREF measures overall quality of life as it encompasses other factors (such as, environment, employment and spirituality) outside of health-related quality of life. Power et al. (1999) similarly suggest that the WHOQOL-100 encompasses a broader view of quality of life than many other quality of life measures, citing the inclusion of the social relationships and environment domains.

Whilst generic quality of life measures allow for scores to be compared between different population groups, they fail to focus on issues of particular concern for individuals with various conditions or diseases (Fayers & Machin, 2007). Generic health-related quality of life instruments, therefore, may not be responsive to a change for individual diseases (El-Serag, Olden & Bjorkman, 2002). Osborne, Bindemann, Noble and Reed (2014) found that there were differences between perceived importance of areas of quality of life for healthy individuals compared to those with long-term illness, whereby, healthy participants noted relationships and family as more important to quality of life and participants with a long-term condition noted pain, fatigue and sleep as more important. Similarly, Arnold et al. (2004), when comparing quality of life domains across a variety of long-term conditions, suggest that there are differences between different groups of individuals with long-term conditions and healthy individuals on physical, social and psychological functioning.

El-Serag et al. (2002) suggest that disease-specific measures are designed to detect changes in health-related quality of life that may not be targeted by generic instruments. Bowling (2001) proposes that disease-specific measures should aim to be more clinically and socially significant in relation to specific conditions and also be able to discriminate more finely between patients' levels of severity of the condition and be more sensitive to any clinical outcomes. Certainly, McGee (2004) suggests that the drive behind the development of disease-specific instruments is to focus on the most salient aspects of quality of life for individuals with a specific health condition. Moreover, they state that a quality of life measure should be developed to be sensitive to change in aspects of life believed to be most affected by the condition concerned and its

treatment. This suggests that a disease-specific quality of life measure may be representative of, and better able to detect change in, quality of life for women with PCOS.

Currently, there is only one disease-specific quality of life measure for women with PCOS, the PCOS Questionnaire, otherwise known as the PCOSQ (Cronin et al., 1998). The PCOSQ is a 26-item quality of life questionnaire for use with women with PCOS, developed with a clinical sample of US women with PCOS (Cronin et al.). Referred to as a measure of symptom-bother by some (Malik-Aslam et al., 2010), several limitations of the PCOSQ have been identified including poor content validity (Malik-Aslam et al.) and inappropriate development techniques, according to relevant literature (DeVellis, 2012). In addition, the inclusion criteria for the PCOSQ development excluded some women with PCOS, as diagnosed by the Rotterdam 2003 criteria, and was developed using women with PCOS who were currently seeking help from a healthcare professional within the US healthcare system (see Chapter Two and Five for more information). As such, in order to measure the impact of PCOS on quality of life for women in the UK the development of a disease specific questionnaire is necessary to measure and address issues experienced by individuals with different symptom profiles, according to the Rotterdam 2003 criteria that may not be present in other conditions.

1.7.3 PCOS and Quality of Life

A literature search was conducted to locate published studies exploring PCOS and quality of life. The search strategy included two main approaches: electronic searches of computerised databases including PsychArticles, PsychInfo, PubMed, Science Direct, EBSCO and Google Scholar; and also a search of citations in papers identified by the electronic search. The search was completed using keywords such as: 'PCOS', 'Polycystic Ovary Syndrome', 'Quality of Life', 'Health-Related Quality of Life' and 'QoL'. The search revealed 41 papers which explore PCOS and quality of life using quantitative methods. Eight of these were medical or lifestyle interventions, eight were reviews, two explored the experiences of adolescents with PCOS, six were concerned with scale development and validity testing (discussed in Chapter Five) and two focused on the symptom of infertility. The remaining 15 quantitative papers are described in detail in Table 1.1. Overall, PCOS has been shown to have large negative effects on health related quality of life (Cinar et al., 2011; Coffey et al., 2006; Hahn et al., 2005).

Table 1.1

A review of quantitative studies exploring quality of life in women with PCOS.

Study	Aim	Participants	Setting	Outcome Measures	Findings
Elsenbruch et al. (2003)	To investigate the impact of PCOS on Health-related quality of life and sexuality	100 women <ul style="list-style-type: none"> - 50 women with PCOS diagnosed according to 1990 NIH criteria - 50 age matched healthy women - excluded for other conditions 	Clinical, Germany <ul style="list-style-type: none"> - Outpatient clinic of the division of Endocrinology, Department of Medicine at the University of Essen 	<ul style="list-style-type: none"> - Questionnaire containing general questions on PCOS-specific issues - SCL-90-R - SF-36 - FLZ (questions on life satisfaction) 	Health-related quality of life measured with SF-36 revealed significant decreased scores for physical role function, bodily pain, vitality, social function, emotional role function in patients with PCOS in comparison to healthy controls.
McCook, Reame & Thatcher (2005)	To evaluate the influence of obesity, fertility status, and androgenism on quality of life.	128 Women <ul style="list-style-type: none"> - Did not specify diagnostic criteria but detailed diagnostic tests - Excluded for other long-term conditions 	Clinical, USA <ul style="list-style-type: none"> - Private endocrinology practice 	<ul style="list-style-type: none"> - WHR - BMI - Clinical assessment of hirsutism – F/G Scoring System - PCOSQ 	Most common health-related quality of life concern was weight followed in descending order by menstrual problems, infertility, emotions and body hair.

Hahn et al. (2005)	To examine the extent of different PCOS symptoms on quality of life, psychosocial wellbeing and sexual satisfaction	<p>170 women</p> <ul style="list-style-type: none"> - 120 women with PCOS (diagnosed with 1990 NIH criteria) - Excluded for other conditions - 50 controls from historical data - Normative data from German population 	<p>Clinical, Germany</p> <ul style="list-style-type: none"> - Department of Medicine, University of Duisburg-Essen 	<ul style="list-style-type: none"> - SF-36 (German) - SCL-90-R (German) - Visual Analogue Scales 	PCOS patients showed significant reductions in quality of life in comparison to control data. BMI and hirsutism scores, but not acne, were associated with physical aspects of quality of life.
Coffey, Bano & Mason (2006)	To examine whether women with PCOS have poorer health-related quality of life than women in the general population and patients with other medical conditions	<p>22 women with PCOS</p> <ul style="list-style-type: none"> - Diagnosed if had polycystic ovaries, menstrual irregularities and/or clinical or biochemical evidence of hyperandrogenism - 96 controls - women attending the Family Planning Clinic (women with PCOS or PCOS type 	<p>Clinical, UK</p> <ul style="list-style-type: none"> - Gynecological and Endocrinology Clinic at St. George's Hospital, London 	<ul style="list-style-type: none"> - SF-36 - PCOSQ - PCOSQ (modified version with reference to PCOS removed for control group) 	PCOS has a negative impact on psychological health-related quality of life even when compared to other serious health conditions (asthma, epilepsy, diabetes, back pain, arthritis and coronary heart disease).

		<p>symptoms were not excluded from control group)</p> <ul style="list-style-type: none"> - Data about other illnesses obtained from Oxford Health and Lifestyle Survey 			
Barnard et al. (2007)	To assess quality of life in a large sample of women with and without PCOS	<p>1359 women (range reported)</p> <ul style="list-style-type: none"> - Up to 424 women with self-reported diagnosis of PCOS - Up to 935 healthy women - Four groups - Women with PCOS taking Anti-Androgens (AA) - Women with PCOS not taking AA - Healthy women taking AA - Healthy women not taking AA 	Online, not UK specific	<ul style="list-style-type: none"> - PCOSQ (modified to include an acne subscale) - SDS 	Women with PCOS had lower quality of life on all seven factors of the modified PCOSQ (emotional disturbance, weight, infertility, acne, menstrual symptoms, menstrual predictability and hirsutism) than healthy controls.

Ching, Burke & Stuckey (2007)	To study quality of life in women with PCOS, compare the findings with population norms and assess if they correlate with reported quality of patient information received.	173 women <ul style="list-style-type: none"> - with PCOS diagnosed with the NIH criteria - Population norm data - Excluded for other long-term conditions 	Clinical, Australia <ul style="list-style-type: none"> - Women's health clinic at the Keogh Institute for Medical Research or the Endocrinology and Diabetes clinic at Sir Charles Gairdner Hospital 	<ul style="list-style-type: none"> - SF-36 - PCOSQ - GHQ-28 - PIQ 	Impaired quality of life and increased prevalence of psychology morbidity in PCOS compared to population norms
Jones et al. (2010)	To compare health-related quality of life of South Asian and white Caucasian women with PCOS	171 women <ul style="list-style-type: none"> - 42 South Asian with PCOS - 129 Caucasian with PCOS - Did not specify diagnostic criteria but detailed diagnostic tests - Normative data from Oxford Health and Lifestyle Survey 	Clinical, UK <ul style="list-style-type: none"> - Gynecology outpatient clinics of two university teaching hospitals in Sheffield and Leeds 	<ul style="list-style-type: none"> - SF-36 - PCOSQ 	Health-related quality of life scores were lower than normative data for both groups. There was no difference in health-related quality of life between the

					Caucasian and South Asian groups.
Kumarapeli, Seneviratne & Wijeyaratne (2011)	To assess psychological distress and health-related quality of life among Sri Lankan women with PCOS	146 women with PCOS - Rotterdam 2003 criteria - 170 age matched controls recruited from community screening	Field & Clinical, Sri Lanka - Data were collected by a team of field investigators & female physicians - Households located and women approached - Only participants who attended local clinics for clinical and biochemical assessment were included	- WHOQOL BREF validated for Sri Lankans - GHQ30	PCOS occurring in South Asians adversely affects their psychological wellbeing and health-related quality of life in comparison to age matched controls.
Açmaz et al. (2013)	To determine which symptoms increased such problems as depression, anxiety, low self-	133 women - 86 women with PCOS diagnosed according to Rotterdam 2003 criteria - Excluded for other physical conditions	Clinical, Turkey - Kayseri Education and Research Hospital of Medicine	- LSAS - RSES - SF-36 - BDI - BAI	The most affecting factors for quality of life among women were irregular menstrual cycle and hirsutism.

	esteem and social worry by classifying PCOS according to symptoms	- 47 healthy volunteers			
Bazargan ipour et al. (2013a)*	To examine the extent of different clinical symptoms in PCOS patients on quality of life.	200 women - Diagnosed according to the Rotterdam 2003 criteria Inclusion criteria: - 15 to 40 years old - Married, Iranian - Not having another cause for infertility (male factor)	Clinical, Iran - Two private gynecology clinic in Kashan, Iran	- MPCOSQ	Most common health-related quality of life concern was menstrual irregularities and infertility, followed by hirsutism, weight, emotion and acne.
Bazargan ipour et al. (2013b)*	To determine associations between health-related quality of life and psychosexual variables in women with PCOS.	300 women with PCOS, divided into three groups: - Hyperandrogenism (HA) & PCO morphology - Menstrual dysfunction and PCO morphology - Menstrual dysfunction and HA and/or PCO	- Clinical, Iran - Two private gynecology clinics	- HADS - BIC - RSES - SF-36 - FSFI	In patients with different phenotypes of PCOS, the effects of mediating variables on health-related quality of life are different.

Bazargan ipour et al. (2014)*	To determine the most significant predictors of the health-related quality of life in patients with PCOS	300 women with PCOS	Clinical, Iran	<ul style="list-style-type: none"> - HADS - BIC - RSES - MPCOSQ - FSFI 	Highest effect of PCOS symptoms on health-related quality of life impairment was exerted by self-esteem, body image and sexual dysfunction.
Benetti- Pinto et al. (2015)	To assess sexual function and quality of life in women with PCOS.	<p>-56 women with PCOS diagnosis according to Rotterdam 2003 criteria.</p> <ul style="list-style-type: none"> - 102 control women with regular menstrual cycles - excluded women with other long-term conditions, those taking anti-depressants and those pregnant. 	<p>Clinical, Brazil</p> <ul style="list-style-type: none"> - Department of Gynecology and Obstetrics 	<ul style="list-style-type: none"> - FSFI - WHOQOL BREF 	Women with PCOS had a worse sexual function in comparison to controls. Body weight was correlated to the worsening of quality of life but not sexual function.
Khomam i et al. (2015)	To assess the impact of various clinical features of PCOS on	<p>796 women diagnosed with PCOS according to Rotterdam 2003 criteria. Aged 15-49.</p> <ul style="list-style-type: none"> - Excluded if diagnosed with other conditions 	<p>Clinical, Iran</p> <ul style="list-style-type: none"> - Referred by gynecologists to the Reproductive 	<ul style="list-style-type: none"> - PCOSQ (translated) 	Hirsutism had strongest impact on health-related quality of life measures.

	health-related quality of life.		Endocrinology Research Center		
Riddhi & Prajakta (2015)	To explore health-related quality of life in women with PCOS.	Women with PCOS between ages 18-45 years.	India	- PCOSQ	In both married and unmarried females, most affected domain was body weight followed by infertility.

Key- BAI: Beck Anxiety Inventory (Steer & Beck, 1997); BDI: Beck Depression Inventory (Beck, Ward, Mendelson, Mock & Erbaugh, 1961); BIC: Body Image Concern Inventory (Littleton, Axsom & Pury, 2005); FLZ: Fragebogen Zur Lebenszufriedenheit (Henrich & Herschbach, 2000); GHQ-28 (Goldberg & Hillier, 1979); FSFI: Female Sexual Function Inventory (Rosen et al., 2000); GHQ-30: (Sumathipala & Murray, 2000); HRQoL: Health-related quality of life; LSAS: Liebowitz's Social Anxiety Scale (Liebowitz, 1987); MPCOSQL: Modified PCOSQ (Bazarganipour et al., 2013c) PCOSQ (Cronin et al., 1998); PIQ: Patient Information Questionnaire; QoL: Quality of Life; RSES: Rosenberg's Self Esteem Scale (Rosenberg, 1965); SCL-90-R: The Symptom Checklist (Schmitz et al., 2000); SF-36: Short Form (Ware & Sherbourne, 1992); WHOQOL BREF (Kumarapeli, Seneviratne & Wijeyaratne, 2006); WHR: Weight/Height Ratio; SDS: Zung Self-Rating Depression Scale (Zung, 1965).

* denotes studies which appear to use the same sample of participants.

The studies detailed in Table 1.1 explore the impact of PCOS on quality of life: the earliest study to explore this found that women with PCOS reported that the condition negatively affected various aspects of their life, including family life, professional activities, leisure activities and physical fitness (Elsenbruch et al. 2003). Barnard et al. (2007), Ching, Burke and Stuckey (2007) and Jones et al. (2010) all report that women with PCOS have an impaired quality of life in comparison to control groups and/or normative data. McCook et al. (2005) identified that the symptom of weight was the highest health-related quality of life concern for women with PCOS, with hirsutism symptoms being the lowest related concern. Hahn et al. (2005) also found that obesity was significantly correlated with quality of life and, they reported that the symptom of hirsutism reduced quality of life. Recently, Benetti-Pinto Ferreira, Antunes Jr. and Yela (2015) reported that the domain of body weight, as measured by the PCOSQ, was correlated to worse quality of life in women with PCOS in Brazil, followed by infertility.

Açmaz et al. (2013) also reported that the most important factors for quality of life among women with PCOS in Turkey, were irregular menstrual cycle and hirsutism. This is supported by Bazarganipour et al. (2013a) who found that for women with PCOS in Iran, the domains of menstrual irregularities and infertility were the most common quality of life concern, followed by hirsutism, weight, emotion and acne. Khomami et al. (2015), however, found that for their sample of women with PCOS from Iran, hirsutism had the strongest impact on quality of life. Therefore, whilst it is evident that the condition of PCOS and its associated symptoms have a negative impact on quality of life in women with PCOS across Asia, South America, the USA, Australia and Europe, the extent to which the different clinical manifestations of the condition impact quality of life differs. Research is needed, therefore, to explore how the symptoms of PCOS, for women in the UK, are associated with their quality of life.

It is clear from Table 1.1 that the majority of papers exploring quality of life in adult women with PCOS are conducted in a clinical setting (13/15). Of the fifteen studies, only two studies were conducted in the UK and both of these studies were conducted in a clinical setting. This suggests that women with PCOS in the UK, who are no longer a part of the healthcare system, may not be considered in studies exploring quality of life.

Across the studies detailed in Table 1.1 the number of women with PCOS who participated was relatively small, with the largest sample in the UK being 424 participants (Barnard et al. 2007). Khomami et al. (2015) did have a larger sample size of 796 women with PCOS, however, all other quality of life studies from Iran used a smaller sample size ($n < 300$). Caution is warranted, however, when interpreting the studies detailed by Bazarganipour et al. (2013a, 2013b, 2014) as there are many similarities between the study samples which suggest that the sample/data used in each study may be the same (sample size, recruitment strategy, inclusion/exclusion criteria). Moreover, whilst eight studies detailed the diagnostic criteria used to diagnose PCOS (three using the 1990 NIH criteria and five using the 2003 Rotterdam criteria), three studies reported only diagnostic tests run to establish PCOS (and no specific diagnostic criteria), one study used self-report data and the remaining three studies did not detail the criteria used. This supports the suggestion that comparative research on PCOS has been disadvantaged by the lack of a consensus definition of PCOS (Ong et al., 2006).

Eight of the 15 studies detailed in Table 1.1 state that they exclude women with other conditions, both long-term conditions and other physical conditions. However, Women with PCOS often experience one or more co-morbid conditions including; type 2 diabetes and impaired glucose tolerance (Legro, Kunesman, Dodson, & Dunaif, 1999; Vrbikova & Hainer, 2009) and thyroid disorders (Janssen, Mehlmauer, Hahn, Öffner & Gärtner, 2004; Kachuei, Jafari, Kachuei & Keshteli, 2012; Nisar et al., 2012; Sinha et al., 2013). Women with PCOS also experience elevated risk factors for developing cardiovascular disease compared to matched controls (de Groot, Dekkers, Romijn, Dieben & Helmerhorst, 2011; Milman & Dokras, 2014; Talbott et al., 1995). Research also suggests that women with PCOS are at an increased risk of developing endometrial cancer (Gottschau, Kjaer, Jensen, Munk & Mellemkjaer, 2015; Milman & Dokras; Haoula, Salman & Atiomo, 2012; Shafiee et al., 2014).

In addition to physical co-morbidities, women with PCOS are also more likely to experience psychological co-morbidities, including anxiety and depression (Deeks, Gibson-Helm & Teede, 2010; Esler, Travers, Guttikonda, Dixon & Lewis, 2007; Månsson et al., 2008; Rasgon et al., 2003; Rassi et al., 2010). Lipton, Sherr, Elford, Rustin and Clayton (2006) found that in a sample

of women with PCOS over 74% had clinical levels of anxiety, over 30% had clinical levels of depression and just over 29% of women had clinical levels of both depression and anxiety. It is clear that women with PCOS are more likely to experience co-morbid conditions, both physical and psychological. As these papers do not specify if co-morbidities were included or excluded there are, therefore, only two published papers in the UK (Barnard et al., 2007; Coffey et al., 2006) and four studies outside of the UK (Bazarganipour et al., 2013a, 2013b, 2014; Riddhi & Prajakta, 2015) that explore quality of life for women with PCOS without excluding for common co-morbidities. As such, there is a need for research which explores the impact of PCOS, which is inclusive of any presenting co-morbid conditions, on quality of life.

Nine of the fifteen studies explored the impact of PCOS on quality of life in comparison to a control group or population norms. Of those nine, eight reported that women with PCOS experienced a decreased quality of life in comparison to controls in both psychological and physical domains. The remaining study reported that women with PCOS reported reduced quality of life in the self-assessment of health domain (of the WHOQOL-BREF) but not others, in comparison to controls. Moreover, seven of the studies (Açmaz et al., 2013; Barnard et al., 2007; Bazarganipour et al., 2013a, 2014; Hahn et al., 2005; Khomami et al., 2015; McCook et al., 2005) detailed the impact of specific PCOS symptoms on quality of life, suggesting that hirsutism, BMI and menstrual irregularities were associated with a negative impact on quality of life.

Recent research exploring quality of life in women with PCOS has been published from Iran (Banaganipour et al., 2013; Khomami, Tehrani, Hasemi, Farahmand & Azizi, 2015), India (Riddhi & Prajakta, 2015) and Brazil (Benetti-Pinto et al. 2015). Like the other studies detailed above (Açmaz et al., 2013; Barnard et al., 2007, Hahn et al., 2005; McCook et al., 2005), these studies focus on the impact of specific symptoms of PCOS, such as body weight, infertility, hirsutism and irregular menstruation, on quality of life rather than investigating overall quality of life. Similarly to those studies detailed above, the research found that symptoms such as fertility, irregular menstruation, hirsutism and BMI had the strongest impact on quality of life in women with PCOS. This suggests that PCOS can have a negative impact on quality of life, and that the impact of this condition and its symptoms on quality of life can vary across countries. As such,

whilst there is a growing body of research which details the quantitative impact of PCOS on quality of life, there is little research which explores the impact of PCOS and its symptoms on quality of life, from the perspective of women with PCOS in the UK.

1.8 PCOS and Qualitative Research

The literature search detailed above (in Section 1.7.2) also revealed three papers (Amiri et al., 2014; Taghavi et al., 2015; Washington, 2008) which have explored the impact of PCOS on quality of life qualitatively. The paper by Washington (2008) details quality of life as pertaining to daily activities, self-esteem and employment experiences. This suggests that not all domains of quality of life (Testa & Simonson, 1996; The WHOQOL Group, 1994), including the social, physical and psychological domains, were explored in their study. The other two papers (Amiri et al.; Taghavi et al.) were published within the last two years. Therefore, in order to gain a better understanding of the experience of PCOS and how it was perceived by women with the condition, an additional literature search, using the same databases, was performed. This search used keywords such as: 'PCOS', 'Polycystic Ovary Syndrome', 'Qualitative' and 'Experience'. It revealed 12 studies which explored PCOS using qualitative methods. Two of these were unpolished doctoral dissertations (Castillo, 2008; Washington, 2005) and two studies explored support for women with PCOS (Holbrey & Coulson, 2013; Percy et al., 2009). The remaining eight studies, their methods and findings, are detailed in Table 1.2.

Overall, the papers detailed in Table 1.2 suggest that PCOS can have a negative impact on women with the condition. The first qualitative study exploring the experience of the condition found that women with PCOS felt stigmatised due to their condition and its symptoms (Kitzinger & Willmott, 2002). Similarly, Snyder (2006) and Weiss and Bulmer (2011) both suggest that women with PCOS identified themselves as different to other women and that participants were negatively impacted by the condition. Indeed, Washington (2008) reports that women with PCOS are negatively affected by the condition and this impact was due to symptoms experienced. Crete and Adamshick (2011) found that women with PCOS aimed to manage their condition in such a way, that they could achieve a high quality of life. Whilst there is little qualitative research exploring the impact of PCOS on quality of life directly, the studies discussed demonstrate that PCOS can have a negative impact on women with the condition.

Moreover, these studies demonstrate the utility of qualitative approaches for gaining understanding about the experience of living with PCOS.

Of the qualitative studies discussed in Table 1.2, only one study was conducted with participants from the UK (Kitzinger & Willmott, 2002). This study also analysed data using a feminist perspective which suggests that analysis was not data led but led by a pre-existing theoretical framework, which may not be a complete reflection of the data. Moreover, three studies explored the experiences of women with PCOS with a confirmed diagnosis, recruited through a clinical setting (Crete & Adamshick, 2011; Synder, 2006; Taghavi et al., 2015). As two of these studies are from the USA, the experiences reported by participants may not be applicable for women in the UK due to the differences in healthcare systems. The most recent qualitative research (Amiri et al., 2013, 2014; Taghavi et al., 2015) is based on an Iranian population and it is possible that the participant's perception of quality of life could be influenced by their spiritual, religious and personal beliefs (WHOQOL Group, 1994). As Taghavi et al. state, for many women in Iran it is forbidden for menstruating women to perform some religious acts such as prayer. In addition, in Islam and Judaism it is forbidden for a man to have intercourse with his wife during menstruation (Taghavi et al.). As such, the findings of this body of research may not be applicable for women outside of Iran, or in the UK where spiritual, religious and personal beliefs may have a different impact on quality of life (Fleck & Skevington, 2007).

Table 1.2

A review of qualitative studies exploring the experience of living with PCOS.

Study	Aim	Location	Participants	Method	Findings
Kitzinger & Willmott (2002)	To explore women's experiences of PCOS, from a feminist perspective, and investigate how women with PCOS negotiate their identities as women.	UK	30 women with PCOS - Self-reported diagnosis - Recruited via Verity (a UK PCOS charity) - 21 - 42 yrs. old	- Semi Structured Interviews - Thematic Analysis	PCOS is a stigmatising condition. Women reported feelings of being 'freakish, abnormal and not proper women'
Snyder (2006)	To uncover the meaning of living with PCOS	USA	12 women with PCOS - women recruited through health care practice - confirmed diagnosis - 21 – 48 yrs. old	- Interviews - Thematic Analysis	PCOS is a syndrome that impacts women both physically and psychosocially.
Washington (2008)	To gain an understanding of the impact of PCOS on women's quality of life (daily activities, self-esteem and employment experiences)	USA	10 women with PCOS - Self-reported diagnosis - Recruited from online support groups - 25 – 39 yrs. old	- Informal conversation interview approach followed by a modified standardised structured interview approach - Thematic Analysis	Employment and activities of daily living were reported to have a moderate negative impact due to symptoms such as pain, fatigue and mood swings.

Crete & Adamshick (2011)	To describe the lived experience of women with PCOS in the management of their disorder and the meaning of that experience for them.	USA	10 women with PCOS - Participants identified from gynecology network within hospital - 20 – 50 yrs. old	- Interviews - Hermeneutic phenomenological reflection	Women with PCOS face many challenges in managing their disorder and desire to gain control, balance and well-being.
Weiss & Bulmer (2011)	To explore the psychosocial effects of living with PCOS through the experiences of young women diagnosed with the endocrine disorder.	USA	12 women with PCOS - Required to have a clinical diagnosis - Recruited from College campuses - 18 – 23 yrs. old	- Interviews - Used a coding analysis based in phenomenology - Constant comparative method	Participants in this study faced numerous physical, social and emotional challenges on a daily basis.
Amiri et al. (2013)	To study the life experiences and concerns women with PCOS have.	Iran	20 Iranian women with PCOS - 18 to 39 years old	- Interviews - Deductive and inductive content analysis	Health care professionals working with PCOS patients should consider providing peer support groups.
Amiri et al. (2014).	To clarify the dimensions and components of quality of life in Iranian women with PCOS	Iran	23 Iranian women with PCOS - Patients at the Reproductive Endocrinology Research Center	- Interviews - Qualitative content analysis	The most important factors affecting quality of life in women with PCOS are role-functioning, physical, mental, emotional,

			<ul style="list-style-type: none"> - Diagnosed according to Rotterdam 2003 criteria - 18 – 40 yrs old - Excluded if had any co-morbid conditions 		cognitive and social domains.
Taghavi et al. (2015)	To generate an in-depth understanding of Health-related quality of life in Iranian women with PCOS.	Iran	<p>20 Iranian women with PCOS</p> <ul style="list-style-type: none"> - outpatient clinics in Yasuj and Kashan (Iran) - Diagnosed according to Rotterdam 2003 criteria - Married, 21-34 years old - Not taking any medications 	<ul style="list-style-type: none"> - Interviews - Thematic Analysis - Qualitative Content Analysis 	Women report substantial effects of PCOS on their quality of life. It is necessary to take a holistic approach to patient care beyond treating physical symptoms.

Note: This table and discussion excludes those qualitative studies published by the author of this thesis.

The studies in Table 1.2 detailed a phenomenological, thematic or content analysis approach to data analysis. However, it is unclear from the papers exactly how these analyses were completed. Each of the thematic analysis papers reported slightly different steps of the analytical process (Kitzinger & Willmott, 2002; Snyder, 2006; Washington, 2008), with only the Taghavi et al. (2015) paper detailing the guidelines of Braun and Clarke (2006). Thematic analysis was, until 2006, a 'poorly demarcated, rarely-acknowledged' method of data analysis (Braun & Clarke, p. 4). However, since Braun and Clarke's publication of specific guidelines for conducting a thematic analysis, qualitative researchers can now utilise appropriate vocabulary and conduct a similar methodical analysis. There is a need therefore, for qualitative research which explores the experience of PCOS, which clearly details the analytical procedure undertaken.

In the first qualitative study exploring PCOS, Kitzinger and Willmott (2002) recommended that further qualitative research exploring how women experience PCOS was 'desperately needed' (p.359), in order to give a voice to women with PCOS. Moreira and Azevedo (2006) later stated that qualitative approaches could contribute significantly to understanding the psychological impact of PCOS and therefore suggested that qualitative methods should be incorporated into future PCOS studies. However, a decade on from Moreira and Azevedo's statement, the available qualitative research is still limited to less than 10 published papers (Amiri et al., 2013, 2014; Crete & Adamshick, 2011; Kitzinger & Willmott, 2002; Snyder, 2006; Taghavi et al., 2015; Washington, 2008, Weiss & Bulmer, 2011), with only one paper exploring experiences of women with PCOS in the UK. As such, the field of PCOS research is still overwhelmingly dominated by quantitative, and largely medicalised research, whereby the experience of the condition is missing (Bazarganipour et al., 2015; Ma et al., 2013). Therefore, in order to gain an understanding of the perspective of women with PCOS, with regards to their quality of life and experience of the condition, more qualitative research is necessary (Kitzinger & Willmott, 2002; Ma et al., 2013; Moreira & Azevedo, 2006; Taghavi et al., 2015).

1.9 Summary

PCOS is a long-term condition characterised by symptoms including alopecia, infertility (Elsenbruch et al., 2003), acne (Coffey et al., 2006), obesity (Goudas & Dumesic, 1997), hirsutism (Oláh, 2004) and menstrual irregularities (Hahn et al., 2005). To date there have been eight published papers which explore PCOS from a qualitative perspective (Amiri et al.,

2013, 2014; Crete & Adamshick, 2011; Kitzinger & Willmott, 2002; Snyder, 2006; Taghavi et al., 2015; Washington, 2008; Weiss & Bulmer, 2011). However, none of these has explored the experience of women with PCOS in the UK outside of a feminist framework (see Kitzinger & Willmott, 2002), nor have they explored quality of life from a qualitative perspective. As such, there remains a need to gain an understanding of the experience of PCOS for women in the UK and also the impact of PCOS on quality of life from the perspective of women with the condition.

It is clear that there is a lack of consensus over a 'gold standard' definition of quality of life (Bowling, 2001; Rapley, 2003). However, domains which are commonly associated with quality of life include physical and psychological domains, social domains and environmental domains (Fayers & Machin, 2007; Testa & Simonson, 1996; WHOQOL Group, 1994). Moreover, quality of life concerns the individual's perspective, their goals and their expectations (Carr et al., 2001; Testa & Simonson, 1996). Indeed, Fayers & Machin suggest that quality of life is poorly defined and has different meanings to different individuals. Therefore, it is necessary to explore how women with PCOS in the UK perceive and define their quality of life.

Women with PCOS are also likely to live with co-morbid conditions such as cardiovascular disease (Sirmans, Parish, Blake & Wang, 2014) and diabetes (Legro et al., 1999; Shorakee, Joham & Teede, 2015). In addition, women with PCOS are more likely to experience depression and anxiety (Deeks, Gibson-Helm & Teede, 2010; Rasgon et al., 2003). Whilst there is a growing body of quantitative research that explores incidences of co-morbid conditions in women with PCOS (Annagür et al., 2015; Betheas & Nestler, 2008; Dokras, 2012; Rasgon et al., 2003), there has yet to be research that qualitatively explores how women with PCOS experience and manage their condition on a day-to-day basis, and any presenting co-morbid conditions. Therefore, qualitative research is also needed to further understand how women with PCOS live with the condition, and any co-morbid acute or long-term conditions.

This chapter also presented research which explored quality of life from a quantitative perspective. However, it was identified that the existing PCOS quality of life measure, the PCOSQ (Cronin et al., 1998), was seen more as a measure of symptom-bother (Malik-Aslam et al., 2010) than a quality of life measure and was subject to several developmental issues

(see Chapter Two and Five for more detail). As such, there is a need for a UK, disease-specific, quality of life measure for women with PCOS which focuses on the most salient aspects of quality of life for those women (McGee, 2004). Therefore, it encompasses the physical, psychological and social domains of health that are influenced by a person's experiences, beliefs, expectations and perceptions (Testa & Simonson, 1996).

Finally, this chapter detailed that treatment of PCOS is symptomatic (Rosenfield, 2008) with medical treatments and medications such as the oral contraceptive pill and metformin, commonly prescribed (Herriot et al., 2008; Teede et al., 2006). Alternatively, women with PCOS undertake lifestyle changes, such as diet and exercise, in order to help them manage their symptoms (Harris-Glocker et al., 2010; Hart & Norman, 2006). However, there are few non-medical treatment or intervention options available for women with PCOS that aim to improve quality of life. As such, an intervention which aims to improve quality of life in women with PCOS is needed.

1.10 Research Aims

The overarching objective of this thesis is to further understanding, and improve quality of life of women with PCOS in the UK. As such, this research aims:

1. To investigate and identify how women with PCOS in the UK perceive and define their quality of life;
2. to further understanding of the impact of PCOS on quality of life of women in the UK from their perspective;
3. to explore and gain an understanding of how women with PCOS in the UK live with and perceive their condition, and any co-morbid conditions, on a daily basis;
4. to develop a scale which will enable measurement of quality of life in women with PCOS in the UK, as defined by them, which is inclusive of all aspects of quality of life that may impact women with PCOS;
5. to test the validity and the reliability of a PCOS quality of life scale for women in the UK according to current scale development guidelines;
6. to investigate the prevalence of symptoms in women with PCOS in the UK and their association with quality of life;
7. and to identify, develop and test an intervention aimed at increasing quality of life in women with PCOS.

Chapter Two -Methodology

In order to answer the research aims presented in the previous chapter, consideration needs to be given to how this can be best achieved. This chapter first reiterates the aims of this thesis, and then discusses how each of these aims will be addressed. This includes a discussion of the ontological and epistemological approach taken, the benefits of a mixed methods approach, and an introduction to the data collection and generation methods that will be utilised. In addition, it will discuss the issues with measuring quality of life in women with PCOS currently, and how to overcome these, and also how quality of life can be improved in women with PCOS. Finally, it will reflect on issues associated with using an online sample.

2.1 Introduction

In order to further understand, measure and improve quality of life in women with PCOS it is necessary first to identify how women with PCOS perceive and define their own quality of life and to explore the impact of PCOS on quality of life from the perception of women with the condition. Moreover, it is essential to investigate how women with PCOS live with, and perceive, their condition and any co-morbid conditions on a day-to-day basis. It is also necessary to create an item pool for scale development purposes, in order to create a measure that represents how women with PCOS perceive and understand their own quality of life; and finally, to identify, develop and test a suitable intervention to improve quality of life in women with PCOS.

In order to achieve the aims of this thesis a mixed methods approach is necessary. Exploration of quality of life may be best investigated through the use of qualitative methodology. However, to address the latter research aims, including the development and testing of a new PCOS quality of life scale and the development and testing of an intervention aimed at increasing quality of life in women with PCOS, a quantitative approach will be needed. Indeed, Rohleder and Lyons (2015) suggest that research in psychology can benefit from drawing on a variety of sources of data in order to better understand a phenomenon. As such, a mixed methods approach is useful in order to achieve these aims.

2.2 Ontology and Epistemology

In research, the method of data collection, method of analysis, and theoretical framework should be aligned in order to produce research which can meet the research aims (Braun & Clarke, 2006; Chamberlain, 2015). As such, the researcher's theoretical perspective: ontology and epistemology, need to be considered. Ontology has been defined as the assumptions a researcher makes about the nature of the world and the phenomena in it, whereas, epistemology is concerned with the assumptions a researcher makes about how we can investigate the phenomena (Chamberlain, 2015; Coyle, 2016). Within ontology, there are two overarching ontological positions, realism and relativism (O'Reilly & Kiyimba, 2015). Realism is the idea that there is a reality that exists independently of an individual's beliefs or understandings of a phenomena (O'Reilly & Kiyimba, 2015), whereas relativism assumes that reality is dependent on the way we come to know it (Coyle, 2016). A realist approach hopes to generate knowledge that captures and reflects what is happening in the real world (Willig, 2013). Indeed, Willig (2013) suggests that a realist will position the researcher as someone who uses research skills to investigate phenomena and uncover evidence, rather than the researcher being an individual who constructs the findings. Furthermore, Willig (2013) suggests that a realist approach assumes that there are processes of a psychological nature which exist and can be identified. This thesis fits within a realist ontology, in that the research is undertaken with an assumption that reality is not dependent on how we come to know it, but that it exists independently to an individual's beliefs.

Positions within a realist ontology can vary from the 'naïve' realist, there is a direct relationship between what the researcher sees and what is going on, to the 'critical' realist (Willig, 2013). The critical realist "admits an inherent subjectivity in the production of knowledge" (Madill, Jordan & Shirley, 2000, p.3) or, as Willig (2013) defines it, a critical realist approach does not assume that data is a direct reflection of what is going on in the world, but that the data needs to be interpreted in order to further our understanding of the phenomena. Coyle (2016) defines critical realism as a reality that 'exists independent of the observer' (p.15) but claims that reality cannot be known with certainty. Similarly, Clarke, Braun & Hayfield (2015a) suggest that 'reality is 'out there'' (p.224) but that access to this reality is always mediated by socio-cultural meanings, and the researcher's interpretation. They further suggest that an individual's world provides access to their particular version of reality and that the researcher produces an interpretation of this reality. Willig (2013) similarly suggests that when conducting qualitative research, a critical realist may find it necessary to 'dig deeper' and interpret the participant's

data to enable them to find any underlying factors that are beyond the participant's knowledge. Critical realism, therefore, 'admits an inherent subjectivity in the production of knowledge' (Madill, Jordan & Shirley, 2000, p.3). A critical realist researcher, therefore, assumes that the data is the participant's version of reality and, as such, there are different perspectives of reality (Maxwell, 2012). However, these may be mediated or interpreted in order to uncover factors which are unknown to the participant.

Chamberlain (2015) suggests that it is difficult to discuss ontology and epistemology separately because they are 'inevitably intertwined' as you cannot discuss one, without the other (p.15). Similarly, Coyle (2016) suggests that discussions often slip between the two. These terms, or references to them, are often used interchangeably within the literature, for example, Willig (2013) refers to realism as an epistemology, whereas Coyle (2016) refers to realism as an ontology. Furthermore, it is argued, that unlike other ontological perspectives, critical realism encompasses both ontology and epistemology (Bergin, Wells & Owen, 2008). That is, critical realism assumes that a researcher can make assumptions about the world (that there is a reality - ontology) and how a researcher can investigate this (it is necessary to interpret this reality – epistemology) (Maxwell, 2012). Bergin et al. (2008) suggest that it is this combination of ontology and epistemology that differentiates critical realism from other theoretical positions. As such, the research for this thesis was conducted within a critical realist approach which suggests that reality exists independently to what can be observed, but it cannot be known, from the perspective of the researcher, with certainty (Coyle, 2016).

2.3 Mixed Methods Research

The combination of qualitative and quantitative methods is known as mixed methods research (Lyons, 2016). It has been suggested that critical realism supports a range of research methods (Bergin, Wells & Owen, 2008). Indeed, Healy and Perry (2000) suggest that within a critical realist framework, both qualitative and quantitative research is appropriate. Krauss (2005) similarly suggests that within critical realism, the divide between quantitative and qualitative research is replaced with 'an approach that is considered appropriate given the research topic of interest' (p.762). Consequently, within a critical realist approach, the methods of data collection and analysis should be guided by the research aim; whereby, the most effective methods to answer the research question may be a combination of both qualitative and quantitative methods (McEvoy & Richards, 2006).

Pragmatism is a similar approach to critical realism, in that it proposes research methods should be guided by the research aim (Johnson & Onwuegbuzie, 2004). Feilzer (2010) suggests that the most important question in pragmatism is whether the research conducted has helped the researcher to find out what they want to know (Hanson, 2006). O'Reilly & Kiyimba (2015) suggest that pragmatism focuses on the compatibility of combining qualitative and quantitative methods, rather than on the differences of epistemologies. Certainly, it is suggested that a pragmatic approach enables researchers to be flexible in the investigative techniques they employ (Onwuegbuzie & Leech, 2005).

Creswell (2003) argues that for mixed methods researchers, pragmatism opens the door to different forms of data collection and analysis in mixed methods studies. Indeed, it is suggested that pragmatic researchers are in a better position to use qualitative research to inform quantitative research and vice versa (Onwuegbuzie & Leech, 2005). Within mixed methods research qualitative approaches are often used in the preparatory stages of quantitative research (McEvoy & Richards, 2006). Creswell (2003) describes the mixed methods process as sequential, whereby the researcher expands on findings of one method, with another method. Within this thesis, this is exemplified through the use of qualitative methods to explore how women with PCOS define quality of life, and the consequential use of these qualitative findings in the scale development process. This use of qualitative data to inform scale development items is common practice in scale development (DeVellis, 2012; Kelly, Jenkinson & Ziebland, 2013; Streiner & Norman, 2008) and has been employed in quality of life scales for other health conditions such as diabetes (Bradley et al., 1999), stroke (Williams, Weinberger, Harris, Clark & Biller, 1999) and endometriosis (Jones et al., 2001).

Mixed methods research has been defined as describing “study designs that employ quantitative and qualitative methods in one or more phases of research that investigates the same underlying phenomena” (Vroman, 2015, p. 301). This is similar to the definition provided by Johnson et al. (2007) who suggest that mixed methods is “the type of research in which a researcher...combines elements of qualitative and quantitative research approaches for the broad purposes of breadth and depth of understanding” (p. 123). Furthermore, Johnson et al. suggest that mixed methods can form a single study, or a programme of research whereby both qualitative and quantitative methods are used across a set of studies which are closely related; such as those studies detailed in this thesis.

Denscombe (2008) suggests that mixed methods approaches have been previously used to allow for a more complete picture of the data to be produced and as a way of developing analysis and building on initial findings. Utilisation of a mixed methodology can potentially lead to a richer understanding of a phenomenon than does a single approach (Yardley & Bishop, 2008). Indeed, Dures et al. (2013) suggest that the use of mixed methods research in health psychology yields conceptually informative and clinically relevant research data. Similarly, Rohleder and Lyons (2015) suggest that both qualitative and quantitative methods are needed to ensure full understanding of psychological phenomena. As such, qualitative research does not need to be set in opposition to quantitative research as qualitative research often asks different but complementary questions (Rohleder & Lyons, 2015). Indeed, Vroman (2015) suggests that mixed methods offer researchers multiple perspectives on what is important and relevant when seeking answers to health related research questions.

Moreira and Azevedo (2006) recommend that qualitative approaches should be utilised, in order to further understanding of the psychological impact of a health condition, in addition to traditional quantitative approaches. As such, in order to investigate the research aims of this thesis, it is evident that a mixed methods approach, which utilises both qualitative and quantitative approaches, would be beneficial to further understanding of PCOS and its impact on quality of life. The research within this thesis will be conducted within a critical realist approach. It is recognised, however, that through using mixed methods to answer the overarching research aim (to further understanding and improve quality of life in women with PCOS in the UK), there is also a pragmatic element to the methods used throughout the thesis.

2.4 Qualitative Research

Smith (2015) suggests that qualitative research is concerned with exploring, describing and interpreting the personal experiences of individuals. Within qualitative research there are different approaches to research and research methods that are based on different theoretical assumptions (Lyons, 2016). Consequently, Chamberlain (2015) proposes that method, methodology, theoretical perspective and epistemology are all elements which should be aligned in order to produce coherent research. Similarly, Braun and Clarke (2006) recommend that, within research, the theoretical framework and methods need to match the research aims. Therefore, in order to answer the research aims outlined in Chapter One, the ontological and epistemological position and the method of data collection and analysis, were considered prior to the collection of qualitative research.

There are two types of qualitative research, little q and big Q (Kiddler & Fine, 1987; Willig, 2013). Big Q refers to qualitative research which rejects the possibility of discovering universal meaning but also highlights the role of the researcher as active in the research process (Clarke, Braun & Hayfield, 2015). Small q research (Kiddler & Fine, 1987) refers to qualitative research which is structured, categorises and quantifies qualitative data systematically (Coyle, 2016). As such, the qualitative research detailed in this thesis fits within the Big Q type of qualitative research.

Clarke et al. (2015) suggest that ‘fit’ is important in qualitative research and that all the elements of research design should be conceptually compatible. The method of analysis, therefore, needs to be compatible with a critical realist perspective: one such method is thematic analysis (Braun & Clarke, 2006; Clarke, Braun & Hayfield, 2015). In thematic analysis the researcher takes an active role in theme selection and development (Braun & Clarke, 2006). As such, in accordance with critical realism, the researcher interprets the participant’s version of reality (Clarke et al., 2015). Therefore the qualitative studies in this thesis utilised a thematic analysis approach within a critical realist framework.

2.4.1 Thematic Analysis

Thematic analysis can, and has been, described as a Big Q approach (Clarke, Braun & Hayfield, 2015; Coyle, 2016). Braun, Clarke and Terry (2015) suggest that thematic analysis is an excellent tool for qualitative research in health psychology. It is a method which enables the researcher to identify and interpret themes in qualitative data (Clarke & Braun, 2016). Thematic analysis began to appear in the 1960s and 70s (Clarke & Braun, 2016; Clarke, Braun & Hayfield, 2015), however, it has often been used interchangeably with the term ‘content analysis’ (Braun, Clarke & Terry, 2015; Clarke & Braun, 2016; Clarke et al., 2015). However thematic analysis has now become a widely used method in psychology (Clarke et al., 2015) and there are now systematic guidelines in place for researchers to follow, most notably, those of Braun and Clarke (2006).

Clarke and Braun (2016) suggest that thematic analysis can be used to answer the majority of research aims that may be of interest to qualitative researchers. It can be used to address a large range of qualitative research questions and to analyse most types of qualitative data generated by both large and small, homogeneous and heterogeneous samples (Braun et al., 2015a, 2015b).

Finlay and Gough (2003) suggest that thematic analysis is a fluid, yet systematic process which requires an engaged and reflexive researcher. Similarly, Braun and Clarke (2006) suggest that thematic analysis is a flexible method of analysis which may provide a rich and detailed account of the data.

A good fit between the research aim, theoretical assumptions and approach to thematic analysis is key when undertaking qualitative research using thematic analysis (Braun, Clarke & Terry, 2015). Clarke and Braun (2016) suggest that there are three questions that a researcher should seek to answer before beginning a thematic analysis, these are: What is the researcher's theoretical framework? Is the data to be analysed inductively or deductively? And is the data to be analysed for semantic or latent meanings? The following provides an answer to each of these questions respectively.

What is the researcher's theoretical framework? Thematic analysis is a method, rather than a methodology (Clarke & Braun, 2016). It specifies only the analytical procedures which are focused on theme development (Braun, Clarke & Terry, 2015; Braun, Clarke & Hayfield, 2015a). As such, thematic analysis can be applied flexibly within any of the epistemological frameworks which underpin qualitative research, including realism (Braun & Clarke, 2014; Clarke & Braun, 2016). Braun and Clarke (2006) suggest that thematic analysis is a method 'which works both to reflect reality, and to unpick or unravel the surface of 'reality'' (p.9). As such, the analysis used in this thesis was within a critical realist framework which allowed for the analysis to be grounded within the perspective of the participants whilst allowing for an interpretative analysis (Clarke et al., 2015; Terry, 2016).

Is the data to be analysed inductively or deductively? Thematic analysis can be inductive or deductive (Braun & Clarke, 2006). Deductive thematic analysis refers to viewing the data through a theoretical lens (Braun et al. 2015a). Inductive thematic analysis, however, refers to an analysis which is grounded in the data; it aims to stay as close as possible to the meanings in the data (Braun et al.). Inductive analysis allows for the themes developed to be derived from the data rather than a pre-existing coding frame or researcher preconceptions (Braun & Clarke, 2006). Clarke and Braun (2016) suggest that realist and inductive approaches often cluster together. As such, in order to explore how participants define their quality of life, and how they experience PCOS, an inductive thematic analysis approach was taken. This allowed the

findings of the thematic analysis to be grounded in the participant's data, rather than according to any pre-conceptual framework.

Is the data to be analysed for semantic or latent meanings? This refers to the level of the thematic analysis: a semantic analysis explores the surface meanings of the data and then provides an interpretation of their broader meanings and implications (Braun & Clarke, 2006). A latent analysis, however, would seek to identify underlying concepts (Braun & Clarke). Braun and Clarke (2006) suggest that different combinations of semantic or latent themes are compatible with a range of different epistemological positions; for example, realist, inductive and semantic approaches often cluster together (Clarke & Braun, 2016). In line with a critical realist epistemology, therefore, a semantic thematic analysis was conducted as it allows the analysis to stay close to the participants data (Clarke & Braun, 2016) but there is a level of interpretation by the researcher (Braun & Clarke, 2006). However, it is recognised that within a thematic analysis there is often a combination of elements of both semantic and latent analysis (Braun, Clarke & Terry, 2015).

The thematic analysis used in this thesis was undertaken according to the guidelines of Braun and Clarke (2006) as they provide an accessible, systematic and rigorous approach to theme development (Howitt, 2010). To conduct a thematic analysis, Braun and Clarke (2006) recommend six phases that the researcher needs to follow. These include: familiarising oneself with the data, generating initial codes, searching for and then reviewing themes, defining and naming themes and finally producing a report.

2.4.2 Reflexivity

Reflexivity is a key feature of qualitative research, this refers to acknowledgement of the role the researcher's theoretical commitments, personal understandings and personal experiences have in their analysis (Coyle, 2016). Willig (2013) similarly suggests that reflexivity requires the researcher to be aware of their influence on the analysis and the research process. She states that reflexivity involves 'reflecting upon the ways in which our own values, experiences, interests, beliefs, political commitments, wider aims in life and social identities' have shaped the research process (Willig, 2013, p.10). Larkin (2015) defines reflexivity as an explicit consideration of the ways in which a researcher can influence the data. The researcher needs to consider the ways that they can influence the data in order to be reflexive (Larkin, 2015). Therefore, this section will explicitly consider the impact the researcher could have had on the

data and the ways in which their own personal experiences and understandings can impact the analytical process (Coyle, 2016).

The remainder of this section, therefore, shall be written in first person. Arguably, the most important aspect for reflection is that I was diagnosed with PCOS almost a decade ago. This has the potential to impact the interpretation of the data through consideration of my own experiences of living with the condition. However, as I was diagnosed when I was still relatively young, I have been able to manage my condition through lifestyle changes. As a result I experience very few symptoms, the ones I do experience are limited to hypoglycaemia. Consequently, whilst I have to be aware of my blood sugar levels, it seldom bothers me or requires me to take any action outside of my normal day-to-day activities. The experiences of many of my participants, therefore, are largely different from mine, allowing my interpretation to be grounded in the participants experience, rather than my own experiences or assumptions. To further ensure that my analyses were grounded in the participants' experiences and perceptions, I had regular discussions with my supervision team to discuss the findings of the analysis.

2.5 Methods of Data Generation

As mentioned, the method of data generation, or collection, needs to fit within the epistemological assumptions of the research and research aims (Lyons, 2015). As such, the methods of data collection and data generation are considered and discussed with relation to their 'fit' to the other elements of research design and specifically, the research aims (Clarke et al., 2015).

2.5.1 Photovoice

The WHOQOL Group (1994) define quality of life "as an individual's perception of their position in life in the context of culture and value systems in which they live" (p.3). Similarly, Bowling (2001) suggests that quality of life may mean different things to different individuals. Therefore, in order to identify how women with PCOS perceive their quality of life, it is first necessary for the individual to define their quality of life in relation to their own cultural and value systems. As such, it is important to utilise a data collection method which allows the participant to generate their data free of the researchers input, in order to reflect the participant's perception of quality of life rather than one which is led by the researcher or previous

definitions. One method which can allow the participants to produce data with little interference from the researcher is photovoice.

Photovoice is a process whereby individuals can use photographs to capture their everyday experience of health (Topcu, 2015). Photovoice puts cameras in the hands of the participants allowing them to record their experience (Wang & Burris, 1997). Originally developed as a community-based participatory method (Catalani & Minkler, 2010), photovoice has since been used in many smaller, specific health populations such as long-term mental illness (Thompson et al., 2008), alcohol and drug education (Sharma, 2010), chronic pain (Baker & Wang, 2006), Alzheimer's disease (Wiersma, 2011) and food allergy (Valentine & Knibb, 2011). Specifically, Wang (1999) suggests that photovoice may offer unique contributions to women's health as it allows women to control the process in order to 'express, reflect and communicate their everyday lives' (p.186). Similarly, McIntyre (2003) suggests that through photovoice, women have the opportunity to express themselves in their own images, words and reflections. Utilising photovoice as a data collection technique could help to gain an understanding of the impact PCOS can have on quality of life, and their daily lives, from the perception of women with the condition.

To complete data collection through the photovoice method, participants were given cameras and a notebook and asked to photograph anything they felt had an impact on their quality of life. Participants were also asked to write a diary entry in the notebook to give the picture context, a method that has been used in previous research (Valentine & Knibb, 2011). As photovoice allows the participants to photograph and detail their reality, which is then interpreted by the researcher (through thematic analysis), it is compatible within a critical realist framework (Braun & Clarke, 2006; Coyle, 2016).

2.5.2 Focus Groups

Focus groups are increasingly used in qualitative health psychology research (Willig, 2013). Willig defines focus groups as a 'group interview' whereby the interaction amongst participants is used as a source of data. Braun and Clarke (2013) suggest that focus groups provide naturalistic data encourages participants to talk about the research topic in a 'real' way. Moreover, Braun and Clarke suggest that focus groups can be used as an exploratory tool to begin to research under-researched areas. Similarly, Willig suggests that methods of data collection, such as focus groups and interviews, can be used in combination to explore a

phenomenon. As such, focus groups would provide natural data about the perceptions of living with PCOS, and any co-morbid conditions, on a day-to-day basis. This data could then be used to inform interviews (see section 2.5.3 below) which would allow access to in-depth data around the participant's experiences (Bauer, Yang & Austin, 2004; Lynn, Barbour & Kitzinger, 1999; Morgan, 1996). Lambert and Loiselle (2007) similarly used focus groups to generate initial data and then individual interviews to generate individual, contextualised accounts of the topic under study. However, as detailed in Chapter Four, participants were unable to take part in the focus group aspect of data collection and as such qualitative data was only generated and collected via photovoice and interviews.

2.5.3 Interviews

Semi-structured interviews are widely used in qualitative research as they are compatible with a variety of analysis methods (Lyons, 2015; Willig, 2013), including thematic analysis (Braun & Clarke, 2006; O'Reilly & Kiyimba, 2015). Interviews also allow researchers to gain detailed information about the topic being investigated (Lyons, 2015). Consequently, utilising interviews as a data collection method will add to the findings of the photovoice study, and participant's perceptions of the impact of PCOS on their daily lives can be explored in more depth.

As women with PCOS are often socially isolated (Benson et al., 2009; Kitzinger & Willmott, 2002; Moreira & Azevedo, 2006) it is necessary to utilise data collection methods which are accessible to them. Lyons (2015) suggests that new technologies, such as the internet, offer novel ways to collect data. Furthermore, Lyons (2015) suggests that online interviews allow access to participants who may otherwise not take part in the study and allows a greater reach of participants than traditional face-to-face methods. Similarly, Salmons (2016) suggests that online methods may provide access to socially isolated populations. As such, data collection through interviews in this thesis utilised real-time synchronous online chat software known as Skype™ (Hewson, Vogel & Laurent, 2016) to conduct one-to-one interviews with participants. Hanna (2012) suggests that Skype™ can allow for the same benefits as those one would receive when conducting face-to-face interviews. In addition, Hewson et al. (2016) suggest that visual anonymity in online interviews can improve levels of candour and reduce inhibitions. As Skype™ allows the individual to choose whether they use a camera or not; the participants were able to choose whether they wished to display this visual image. As such, participants were not required to use the available video stream.

2.6 Measuring Quality of Life

In order to answer the overarching research aim of this thesis, to further understanding and improve quality of life for women with PCOS, it is necessary to use a quality of life measure for women with PCOS. Bowling (2001) suggests that quality of life is a multidimensional concept that should incorporate all aspects of an individual's life and that a disease specific scale should be used when disease related factors need to be assessed. Currently, there is only one disease specific quality of life measure for women with PCOS; the PCOSQ (Cronin et al., 1998).

2.6.1 The PCOSQ

The PCOSQ (Cronin et al., 1998) was the first health-related quality of life measure for women with PCOS. It contains 26-items within five domains: emotions, body hair, weight, infertility and menstrual problems. Items include 'during the past two weeks, how much of the time have you felt easily tired?' and 'during the past two weeks, how much of the time have you had trouble dealing with your weight?'. It was developed by clinicians in the USA who specialise in women's health, obstetrics and endocrinology and used a patient sample to develop items (n=10) and perform analyses on the measure (n=100).

Pesudovs, Burr, Harley and Elliott (2007) suggest that patient reported outcome measures are an integral part of research focused on outcomes and that health-related quality of life is an important aspect when assessing the impact of a disease. In addition, they provide quality assessment criteria to assess existing outcome measures, and the development of measures. Pseudovs et al. (2007) argue that, according to the quality assessment tool for evaluation of health status questionnaires, a measure developed on a non-comparable target population is unlikely to include relevant content. In the case of the PCOSQ, this was developed on a clinical US sample of patients with only two of the four possible symptom profiles of PCOS. As such, Pseudovs et al. would argue that it is unlikely to be relevant to all patients with PCOS because population subsets have been omitted from the development process.

Pseudovs et al. (2007) suggest that whilst many measures purport that they measure quality of life; they fail to include the range of dimensions which impact quality of life including emotional and vocational attributes. Pseudovs et al. call this 'construct under representation' (p.665); and, whilst the PCOSQ purports to be a measure of quality of life, it does not measure

all dimensions of quality of life previously identified (Fayers & Machin, 2007; Testa & Simonson, 1996; WHOQOL Group, 1994) and, is described by the developers as a measure which intends to ‘examine disease-related dysfunction’ in women with PCOS (p.1976). The WHOQOL Group (1994) identify several domains that should be included in a health related quality of life scale including: physical, psychological, level of independence, social relationships and environment. Others suggest that quality of life includes physical, emotional and social functioning domains (Fayers & Machin, 2001; Testa & Simonson, 1996). The PCOSQ (Cronin et al., 1998) features five domains, four of which are symptom based (body hair, weight, infertility, menstrual problems), the other being an emotion domain. As such, the PCOSQ fails to discuss any wider domains such as the suggested social domains.

Malik-Aslam, Reaney and Speight (2010) suggest the PCOSQ would be better conceptualised as a measure of symptom bother and psychological well-being rather than a measure of quality of life: arguing that a comprehensive measure of the impact of PCOS on quality of life needs to include all the relevant elements of life that can be affected by PCOS. Similarly, Bowling (2014) suggests that researchers often use the term quality of life to refer to health status, adding that this lack of clarity has led to the use of outcome measures which fail to match the aims of a study.

Streiner and Norman (2008) suggest that when conducting research which aims to measure a psychological construct and the construct is either new, or existing measures overlook a key aspect of the construct, then a new instrument should be developed. Similarly, DeVellis (2012) proposes that when addressing a research aim that requires measurement of a phenomenon, if existing tools are inappropriate for the research aim, then a new tool should be developed. As there are several conceptual and developmental issues with the PCOSQ, with regards to construct validity, sample population, sample size and item development techniques (which are discussed in the next section of this chapter and in-depth in Chapter Five) a new quality of life measure for women with PCOS in the UK needed to be developed in order to effectively meet the research aim of this thesis.

2.6.2 Scale Development

DeVellis (2012) provides a set of eight guidelines that can be used in developing measurement scales. These include: determining clearly what it is you want to measure; generating an item pool; determining the format for measurement; having the initial item pool reviewed by

experts; considering the inclusion of validation items; administering items to a development sample; evaluating the items; and optimising the scale length. Similarly, Streiner and Norman (2008) recommend scale developers follow similar guidelines, including: devising and selecting the items, administering the measure, testing for reliability and testing for validity. Coaley (2010) also recommends that scale developers: set clear aims, define the attribute to be measured, write a plan, write items, select items and administer the items to a trial sample, assess validity and reliability and prepare final documentation for participants. Kline (2000a) also recommends that to develop a psychometric scale; items are developed, administered to a pool of participants and analysed using factor analysis. As such, in accordance with the recommended guidance (Coaley, 2010; DeVellis, 2012; Kline, 2000a, Streiner & Norman, 2008); to develop a new PCOS quality of life scale for women with PCOS in the UK, the following steps were adhered to: generate an item pool; determine the format for measurement; have the initial item pool reviewed by experts; administer items to a development sample; evaluate the items, administer and evaluate the revised item pool; test for reliability and; test for validity.

2.6.2.1 Generating an item pool

DeVellis (2012) recommends that when generating an item pool, each item should reflect the latent variable, in this case quality of life. Furthermore, Streiner and Norman (2008) suggest that measurements of quality of life are dependent upon their definition which may vary from person to person. In addition, they suggest that patients or potential participants are excellent sources of items and that these viewpoints can be gained from qualitative research. Therefore, the item pool for the new scale was generated using the qualitative findings of this thesis (Chapter Three and Four), which discuss how women with PCOS perceive and understand quality of life, and the previous literature in the area. Items were developed according to the guidelines presented by DeVellis, these include, reviewing the initial item pool for: lengthy items, reading difficulty, multiple negatives, double barrelled items, ambiguous references and adjective forms. A large item pool was developed and the 'best' items chosen through methods of analysis (Coaley, 2010).

Whilst the PCOSQ (Cronin et al., 1998) did conduct interviews with patients in order to develop a pool of items, these were limited to the authors own clinical patients. In addition, the authors only conducted a review of the clinical literature and at the time of development of the PCOSQ (1998) there were no qualitative papers available exploring PCOS (the first qualitative

paper was published by Kitzinger & Willmott in 2002). Moreover, Cronin et al. used a narrow diagnostic criteria which excluded two phenotypes of women with PCOS as recognised by the current Rotterdam 2003 criteria (2004). This suggests that the PCOSQ was developed on a limited, non-representative clinical sample which ignores the experiences of those women who have been discharged from the healthcare system or who present with a phenotype that differs from those included in the development interviews. The work presented in this thesis aims to overcome these limitations.

2.6.2.2 Determining the format for measurement

The format of response options for items in a scale should be developed simultaneously to the item themselves (DeVellis, 2012). Aiken and Groth-Marnat (2006) suggest that there are two main categories of response format used in scale development: selected-response format (the participant is forced to choose a response from those given, also known as forced choice) and constructed response format (the participant creates a response). A common item format is a Likert, or rating scale; in a Likert scale the item is presented as a declarative sentence which reflects the underlying variable, and followed by response options that indicate degrees of endorsement of the item (Coaley, 2010; DeVellis). Coaley (2010) suggests that this response format allows individuals to respond more flexibly and more precisely than other response formats. The time frame of responses also needs to be considered and DeVellis recommends that developers select this time frame actively to reflect the construct of interest and intended use of the scale. For the new scale, therefore, responses were in a Likert scale format and timed to reflect the characteristics of PCOS.

Whilst the PCOSQ does have a suitable response format (in the form of a Likert scale), the time frame of responses is contentious. The PCOSQ (Cronin et al., 1998) requires participants to recall over a period of two weeks. As PCOS is largely concerned with a woman's hormonal profile and can impact on a woman's menstrual regularity (Elsenbruch et al., 2013), a two week recall period is arguably insufficient to reflect the construct of interest and intended use of the scale (DeVellis, 2012). Therefore, a recall period of four weeks was used for the PCOSQOL to reflect the average menstrual cycle (NHS, 2014).

2.6.2.3 Have the initial item pool reviewed by experts

DeVellis (2012) recommends that after items have been generated and a response format selected, the initial item pool should be reviewed by individuals knowledgeable in the area, in

this case PCOS. DeVellis suggests asking an expert panel to consider: how relevant they think each item is, to evaluate the items clarity and conciseness and to identify items that may be missing or should be included. This action is related to assessing the content validity of the scale and this is discussed later in the section ‘testing for validity’. As such, the initial item pool was sent to a panel of experts in the area of PCOS, to be reviewed.

Cronin et al. (1998) report that the initial item pool for the PCOSQ was surveyed by health professionals including ‘four endocrinologists, two gynaecologists and two nurse practitioners’ (p.1977). Whilst utilising an expert pool demonstrates good practice within scale development according to DeVellis (2012), their pool was largely medical and this may mean that the psychological aspects of the condition were not adequately reviewed.

2.6.2.4 Administer items to a development sample

The initial item pool should be administered to a large development sample (Coaley, 2010; DeVellis, 2012). A sample size of 300 is suggested to eliminate subject variance (DeVellis, 2012; Nunally, 1978) and as large samples may be more representative of the target population (DeVellis). Therefore in this scale development, the initial item pool was administered to a large sample of approximately 300 women with PCOS.

The PCOSQ (Cronin et al., 1998) was also administered to a development sample via phone interviews, however, whilst the authors did initially identify a sample of 275 eligible women, 147 women declined to participate or did not respond to the authors requests to take part, four women were identified as ineligible and 24 women withdrew (cancelled or missed appointments). Consequently, only 100 patients with PCOS participated in the item reduction phase of development and this sample size may not have been large enough to be representative of the target population or to eliminate variance, particularly as the inclusion criteria did not include two phenotypes of women with PCOS (DeVellis, 2012).

2.6.2.5 Evaluate the items

Once the initial item pool has been administered to a large sample, to identify appropriate items to retain in the scale from the initial large item pool, the items must be analysed (DeVellis, 2012). This involves analysing the item-scale correlations, item variances, item content and item means (DeVellis; Kline, 2000a). However, the principal method to evaluate items is through factor analysis (Coaley, 2010; DeVellis, 2012; Kline, 2000; Nunally & Bernstein,

1994). Factor analysis, when used for scale development, assesses whether individual items relate to a common factor (Coaley, 2010). At this point a coefficient alpha may be calculated to assess the items which have been selected from the initial item pool (DeVellis, 2012) (this is discussed in more depth in ‘testing for reliability’ below). Therefore, to evaluate the initial item pool, items were analysed, a factor analysis was performed and a coefficient alpha was calculated.

Whilst the PCOSQ (Cronin et al., 1998) did conduct a form of factor analysis, the authors state that they used the factor analysis ‘not to reduce items but...to help place items in domains’ (p. 1977). Indeed, prior to conducting the factor analysis, Cronin et al. specified the number of items per domain and only performed the factor analysis on items endorsed by more than half of the sample (minimum 50 participants per item). This suggests that the items were not evaluated according to relevant scale development or statistical guidelines (Coaley, 2010; DeVellis, 2012; Nunally & Bernstein, 1994). Furthermore, it suggests that the scale items were unrepresentative of the intended population and construct as many items which may have had an impact on other participants with PCOS, were excluded.

2.6.2.6 Administer and evaluate the revised item pool

DeVellis (2012) suggests that replicating a factor analysis and its solution on a new population sample, may ‘be the best means of demonstrating generalisability’ (p.158). Kline (2000b) similarly proposes that it is necessary for scale developers to ensure the factor solution can be replicated on a new sample of participants. As such, once appropriate items had been identified from the initial item pool, the revised items were sent to a new, large sample of women with PCOS in the UK. Item evaluation tests such as factor analysis and calculating coefficient alpha, were then performed to evaluate the revised item pool.

The developers of the PCOSQ (Cronin et al., 1998) did not conduct this step, or any of the following steps regarding testing for reliability and validity. As such, the scale development paper itself has not demonstrated any psychometric properties. The validation of the PCOSQ has been completed by other researchers since 1998 (Guyatt et al., 2004; Jones et al., 2004), however, these validations face similar criticisms to many of those levied at Cronin et al. (these are discussed in more detail in Chapter Five). Indeed, Malik-Aslam et al. (2010) suggest that there is a lack of evidence to demonstrate the suitability of the PCOSQ in terms of overall validity.

2.6.2.7 Testing for reliability

Reliability can refer to two factors within scale development: reliability, or stability, of a measure over time and the internal consistency of a measure (Kline, 2000a). Test-retest reliability refers to whether a measure is consistent over time (Coaley, 2010; DeVellis, 2012), this is also known as temporal stability (DeVellis, 2012) which determines whether a test measures consistently from one time to another (Aiken & Groth-Marnat, 2006). A good measure should have high test-retest reliability (Kline). As such, a test-retest was undertaken to test for reliability over time. This involved disseminating the new PCOS scale, to the same group of subjects, at two different time points and computing a correlation between the two scores (Aiken & Groth-Marnat, 2006; DeVellis, 2012; Kline, 2000a).

Internal consistency reliability refers to the extent to which each item within the measure, is measuring the same latent variable (Kline, 2000a), or as DeVellis (2012, p.34) proposes “the homogeneity of items within a scale”. To test the internal consistency of a measure, Cronbach’s alpha coefficient of reliability (Cronbach, 1951) was calculated (Coaley, 2010; DeVellis, 2012; Kline, 2000b).

2.6.2.8 Testing for validity

Nunally (1994) defines validity as ‘the scientific utility of a measuring instrument, broadly state-able in terms of how well it measures what it purports to measure’ (p.83). More simply, validity is whether a scale measures what it intends to measure, in this case the quality of life of women with PCOS (Aiken & Groth-Marnat, 2006; Coaley; 2010). There are three complimentary forms of validity including content related validity, criterion related validity and construct related validity (Coaley; Cronbach, 1990; DeVellis, 2012). However, Cronbach (1990) suggests that whilst these forms of validity are treated as separate entities, they should all be integrated and are not truly separable. Indeed, Aiken and Groth-Marnat (2006) suggest that both content and criterion validity can be used to help further understanding of the construct validity of a measure.

Content validity concerns the extent to which a set of items reflect the content domain (DeVellis, 2012). Within content validity, face validity is also assessed, this refers to the scales physical appearance and whether it looks like it assesses what it intends to (Aiken & Groth-Marnat, 2006). To assess content validity, Streiner and Norman (2008) recommend that experts in the content area, in this case experts in PCOS, give judgement with regards to the content of

items. As such, the initial items developed in the new PCOS scale were assessed by area experts (see Chapter Five).

Criterion validity refers to correlation of a scale to another ‘gold standard’ measure of the construct under study which demonstrates good reliability and validity in the field (DeVellis, 2012; Streiner & Norman, 2008). It is made up of two types of validity: concurrent (correlate the new scale with a criterion measure) and predictive (the criterion is delayed) (Streiner & Norman, 2008). Streiner and Norman give the examples of diagnostic tests whereby an individual may have to await the outcome of an autopsy to confirm predictions, as an example of predictive validity. Concurrent validity, however, may be exemplified by correlating a new scale with a criterion measure which are given at the same time (Streiner & Norman, 2008). As the criterion is not delayed, the new PCOS scale was assessed for concurrent validity. However, as the PCOSQ has been critiqued (Malik-Aslam et al., 2010), there is no ‘gold standard’ measure in the field of PCOS. As such, DeVellis (2012) recommends using a benchmark measure with similar but not identical variables, therefore, criterion validity was assessed with similar measures including the WHOQOL-BREF (The WHOQOL Group, 1998).

Construct validity, developed by Cronbach and Meehl (1955), is concerned with the theoretical relationship of a variable to other variables (DeVellis, 2012), or, whether the test really measures what it claims to measure (Coaley, 2010). Aiken and Groth-Marnat (2006) define construct validity as “the extent to which the instrument measures a particular construct or psychological concept” (p.101), in this case quality of life. A method of testing for construct validity includes gaining experts judgements on whether the measure reflects the construct of interest (Aiken & Groth-Marnat). Another process for testing construct validity is similar to that of concurrent validity, in that test scores are correlated with other accepted measures (Coaley, 2010). This can be referred to as convergent validity (high correlations with other measures of the same construct) or divergent validity (low correlations with measures of different constructs) (Aiken & Groth-Marnat).

2.7 Improving Quality of Life

In order to achieve the overarching aim of this thesis to improve quality of life in women with PCOS, an intervention is necessary. Therefore, once an appropriate PCOS quality of life measure has been developed, an appropriate intervention can be identified, then tested within a population of women with PCOS in the UK. In addition, to aiming to improve quality of

life in women with PCOS, an intervention may also provide further validation (construct validity) for the new PCOS quality of life measurement through an assessment of its sensitivity to change (Streiner & Norman, 2008). That is, assessing whether the measure is able to detect clinically meaningful change. Streiner and Norman suggest that to assess this a mean score of a control group should be compared with a mean score of a treatment group.

2.7.1 Interventions

Fayers and Machin (2001) suggest that traditionally interventions have focused on physical outcomes, rather than quality of life. Correspondingly, there is a large body of literature which explores medical interventions in women with PCOS, however, there is a comparatively small number of studies which have investigated the psychological factors of, and interventions for, PCOS (Farkas, Rigó & Demetrovics, 2014). Andersen (1992) however, suggests that psychological interventions may reduce emotional distress, enhance coping and improve adjustment. Moreover, Bennett (2004) suggests that psychological interventions have been shown to be strong determinants of quality of life. De Ridder (2004) similarly suggests that improving quality of life is a primary goal for psycho-social interventions for individuals with long-term illness. As such psychological interventions may be effective for improving quality of life in women with PCOS in the UK.

Common medical interventions for women with PCOS include the oral contraceptive pill, metformin and clomiphene citrate (CC), commonly known as Clomid. Teede et al. (2006) suggest that oral contraceptive pills are the first line of medical therapy for women with PCOS, as it is thought to control the hormonal manifestations of PCOS including menstrual irregularity and hirsutism (Rosenfield, 2008). In addition, metformin (or glucophage) is the most commonly used pharmaceutical drug in clinical use for treatment of PCOS (La Marca, Artensio, Stabile & Volpe, 2005). For fertility issues which present as a result of PCOS, women with the condition are often prescribed CC which has been used in the United States as the mainstay of ovulation induction in women with PCOS since 1967 (Hill, 2003).

In 2009 the Androgen Excess and Polycystic Ovary Syndrome Society (Moran, Pasquali, Teed, Hoeger & Norman) suggested that lifestyle management should be used as the primary intervention for women with PCOS due to the reported impact on biological symptoms of PCOS, such as ovulatory function. Certainly, there are several non-medical interventions which have focused on lifestyle factors such as diet and exercise (Ehrmann, 2002; Norman, 2006;

Pasquali et al. 2006). Indeed, Wong et al. (2015) explored the impact of a low-glycaemic versus a low-fat diet in women with PCOS. Similarly, Mavropoulous, Yancy, Hepburn and Westman (2005) investigated the impact of a low carbohydrate diet on women with PCOS.

There remains, however, a need for research which explores the impact of psychological interventions on psychological outcomes of PCOS such as quality of life, depression and anxiety (Deeks, Gibson-Helm & Teede, 2010). To date, there are few studies which explore the impact of lifestyle interventions on quality of life in women with PCOS, or the psychological domains associated with the condition including depression and anxiety (Deeks et al., 2010). One study which has explored the impact of lifestyle interventions on quality of life evaluated changes in quality of life of overweight women with PCOS during a 24-week lifestyle modification programme which included diet, exercise and Cognitive Behavioural Therapy (Frène et al., 2015). Frène et al. found that quality of life improved significantly for the participants. Thomson et al. (2010) similarly found that three groups (diet, diet and aerobic exercise, diet and combined aerobic-resistance exercise) in a 20-week lifestyle intervention experienced improvements in quality of life. Furthermore, Stener-Victorin, Holm, Janson, Gustafson and Waern (2013) investigated the impact of acupuncture or exercise on depression, anxiety and quality of life in women with PCOS: they noted an improvement in quality of life scores for both those participants in acupuncture and the exercise group.

Other interventions which aim to improve quality of life in women with PCOS have utilised both medications and lifestyle management. For example, Harris-Glocker, Davidson, Kochman, Guzick and Hoeger (2010) explored the impact of the oral contraceptive pill and lifestyle change with and without metformin in women with PCOS. They found that quality of life scores improved in all groups, including the placebo group. However, interventions which aim to improve quality of life, depression and anxiety in women with PCOS using psychological techniques are few. Indeed, Farkas et al. (2014) propose that there are few studies which have been carried out regarding the efficacy of psychotherapy in PCOS. Farkas et al. detail a study by Rofey et al. (2009) which evaluated the effectiveness of Cognitive Behavioural Therapy in adolescent women with PCOS and found a decrease in depressive symptoms, however they did not explore the impact on quality of life. More recently, Stefanaki et al. (2015) investigated the impact of an eight week mindfulness programme on depression, anxiety and quality of life in women with PCOS. They found that the programme reduced depression and anxiety symptoms and increased quality of life in women with PCOS.

2.7.2 Accessibility to care

The majority of the intervention studies discussed in this chapter detail medical interventions which are made available to women who are, at the time, part of the healthcare system and focus on treating biological symptoms, such as weight and menstrual cycles. Indeed, the DOH (2008) identify that medication has traditionally been the only treatment available to individuals with depression and anxiety. As such, for those women with PCOS who have been discharged from the healthcare system there are two issues: lack of access to medical interventions and lack of accessible psychological interventions.

According to the NHS (n.d.), individuals with long-term conditions use 50% of all GP appointments and their care absorbs 70% of hospital and primary care budgets in England. As such, the NHS suggests that individuals with long-term conditions, such as heart disease, depression and diabetes (all of which are co-morbidly associated with PCOS), should be supported to be as independent and as healthy as they are able to be and to prevent hospitalisation. Furthermore, they suggest that addressing the psychological needs of individuals with long-term conditions, may help to reduce the impact and costs related to them. They example the cost of managing a patient with diabetes and co-morbid depression as being four and a half times higher than the cost of managing a patient with diabetes alone. Whilst figures are not available for women with PCOS, it can be hazarded that the costs for a woman with PCOS may be similar to those for individuals with diabetes due to the similarities in the two conditions which include similar medications, similar co-morbid conditions and similar symptoms.

The Health and Social Care Act 2012 highlighted the importance of mental health, alongside physical health. In addition, in 2008 the UK government launched the Improving Access to Psychological Therapies (IAPT) programme which aims to make psychological therapies for depression and anxiety, specifically CBT, more widely available in the NHS. However, access to psychological therapies is strained with one in 10 people waiting over a year to receive treatment (Mind, 2013) and also due to actual costs of the IAPT scheme exceeding their estimates (Griffiths & Steen, 2013; Radhakrishnan, Hammond, & Lafortune, 2011; Radhakrishnan et al., 2013). Radhakrishnan et al. (2011) suggest that cost-effective, alternative intervention methods are needed. Similarly, Bennett (2004) suggests that psychological interventions should be developed that require minimal input from a healthcare professional, are cost-effect and are brief. Psychological intervention methods that have been identified as

being simple, resource light and cost-effective are positive psychology interventions (DuBois, Millsetin, Celano & Wexlar, 2015; Lyubomirsky & Layous, 2013).

2.7.3 Positive Psychology

Michie and Prestwich (2010) suggest that theory-based interventions can aid understanding of why interventions are effective or not. Moreover, Michie, Johnston, Francis, Hardeman and Eccles (2008) suggest that theory should provide a basis for designing interventions to change behaviour. While a psychological intervention is necessary to meet the aim of this thesis and improve quality of life in women with PCOS, rather than change a health-related behaviour, it is important to first consider the theory upon which the intervention to improve quality of life is based. Positive psychology stems from Seligman's desire for research to focus less on pathology, and more on the positive aspects of human existence.

Seligman (2002) argued that after the Second World War, psychology was concerned mainly with pathology and repairing damage, rather than on fulfilment as an individual and that a change in the direction of psychology from a preoccupation with repairing the worst things in life to building the best things in life, was needed. As Seligman states "psychology is not just the study of disease, weakness, and damage...Treatment is not just fixing what is wrong: it is also building what is right" (p.4.). Seligman urged for a move towards positive health, which rather than focusing on the absence of disease, concerned itself with what makes an individual thrive after illness (Hefferon, 2013). Gable and Haidt (2005) propose that positive psychology is the study of the conditions and processes that contribute to the optimal functioning of individuals and groups. Seligman and Csikszentmihalyi (2000) suggest that positive psychology aims to catalyse a change in the focus of psychology from negative aspects to positive aspects of life. Indeed, Jørgensen and Nafstad (2005) suggest that mainstream psychology gives priority to negative behaviour and various forms of dysfunction, such as depression, racism and violence (Gable & Haidt, 2005), whereas positive psychology aims to concentrate on positive experiences.

Seligman (2002) suggests that positive psychology, therefore, is aimed towards prevention through building of positive human traits. Cohn and Fredrickson (2010) suggest that positive emotions predict mental health, successful coping and also physical health and longevity in those with long-term conditions. Indeed, Fredrickson (2001) developed the Broaden and Build theory which suggests that experiences of positive emotions can broaden an individual's

momentary thought action repertoires, which, in turn, builds the individual's personal resources. More simply, positive emotions can broaden attention, cognition and behavioural repertoires (Cohn & Fredrickson, 2010). As such, positive emotions can have long lasting consequences (Fredrickson, 2001). Certainly, Hefferon (2013) suggests that positive emotions have been found to enhance feelings of mental health. Interventions which employ positive psychology, therefore, may broaden an individual's awareness of positive emotion and the consequential broadened thought-action repertoires may help the individual to integrate the positive psychological behaviour into everyday life (Cohn & Fredrickson, 2010). This reflects the regulation of positive emotions, whereby behaviour change experts may encourage individuals to increase their positive emotions, in order to better help them change behaviour (Michie et al., 2013). Therefore, it is not just those women who are within the healthcare system and 'struggling' with their PCOS (and potential co-morbid conditions) that could benefit from a positive psychology intervention. It is also those women who live with PCOS but do not seek medical help, or who have been discharged from the medical system, that could benefit from a positive psychology intervention.

2.7.4 Positive Psychology Interventions

Lyubomirsky and Layous (2013) define positive activities as "simple, intentional and regular practices" (p.57) which are intended to mimic the healthy thoughts and behaviours associated with naturally happy people; such as counting blessings. This reflects the Broaden and Build theory (Fredrickson, 2001) which suggests that positive emotions can broaden an individual's positive resources. Sin and Lyubomirsky (2009) define positive psychology interventions as "treatment methods or intentional activities that aim to cultivate positive feelings, behaviours or cognitions" (p.468).

Proyer, Wellenzohn, Gander and Ruch (2014) suggest that positive psychology interventions are effective in enhancing well-being and ameliorating depression. Moreover, Huffman, DuBois, Millsetin, Celano & Wexlar (2015) suggest that positive psychology interventions may represent a strategy to increase positive psychological emotions in individuals with long-term conditions. Huffman et al. state that positive psychology "is a branch of clinical and research interventions that uses systematic exercises...to target positive cognitive and emotional states" (p.2). In addition, they state that unlike complex health behaviour interventions, positive psychology interventions are simple and can be delivered remotely, nor do they require participants to have a high level of education or a substantial time commitment

to complete them. Similarly, Lyubomirsky and Layous (2013) suggest that positive psychology activities, such as counting blessings are brief, can be self-administered and are cost effective.

In 2005 Seligman, Steen, Park and Peterson detailed and tested the effectiveness of five positive psychology interventions delivered via the internet, these included: a gratitude visit, listing three good things in life, writing about themselves at their best, using signature strengths in a new way and identifying signature strengths. Participants in the three good things activity demonstrated the most decreased depressive symptoms at the one month, three months and six months post intervention, in comparison to the four other intervention activities. Since Seligman et al.'s study in 2005, gratitude interventions, such as the three good things intervention, have been the most widely used positive psychology intervention in the literature (Wood, Froh & Geraghty, 2010). Similarly, Carson, Muir, Clark, Wakely and Chander (2010) suggest that gratitude has been incorporated into many positive psychology intervention programmes. Hefferon and Boniwell (2011) also propose that gratitude is the underlying concept for many positive psychology interventions.

Fredrickson (2004) suggests that gratitude could broaden and build, by inspiring creative reciprocity and constructing psychological resources, and this could lead to increases in well-being. Indeed, Carr (2011) proposes that whilst the psychological study of gratitude is a recent development; research suggests individuals who engage in positive activities, such as thinking gratefully, become significantly happier (Sin & Lyubomirsky, 2009). Furthermore, McCullough et al. (2002) found that grateful people tend to experience less depression and anxiety than those individuals who were less grateful. Lyubormisky (2007) also suggests that individuals, who are inclined to be grateful, are less likely to be depressed or anxious. Moreover, Wood et al. suggest that gratitude interventions are effective in improving well-being. Gratitude interventions therefore have been found to improve a number of psychological outcomes.

It is worth noting that quality of life has not yet been used as an outcome measure within a gratitude intervention specifically. However, Park (2015) suggests that gratitude is linked to health-related quality of life. It has also been suggested that well-being is incorporated within a definition of health-related quality of life (Bowling, 2001; Fayers & Machin, 2007), others suggest that quality of life is incorporated within well-being (Dodge, Daly, Huyton & Sanders, 2012). Whilst it is clear, that quality of life and well-being are both concepts which are often

confused or used interchangeably (Dodge et al., 2012; Galloway, 2005), Park suggests that positive psychology may help quality of life researchers to expand their focus to include more positive aspects of quality of life.

Wood et al. (2010) suggest that gratitude interventions are often run online and as such, are low cost and, therefore, have the potential to increase access to psychological services if utilised. As such, in order to provide women with PCOS in the UK with a psychological intervention that is easy to access and cost effective, an online positive psychology intervention based on the three good things activity was utilised. Participants were asked to write down three good things that happened to them each day as part of the positive psychology intervention (see Chapter Seven for more details).

2.8 Online Sampling

As mentioned previously, women with PCOS are often socially isolated (Benson et al., 2009; Kitzinger & Willmott, 2002; Moreira & Azevedo, 2006). As such, it is necessary to utilise data collection methods which are accessible to them; such as online data collection techniques (Lyons, 2015). Indeed, Salmons (2016) suggests that data can be collected via any means that individuals use to communicate, such as through computers or mobile devices. Indeed, Hewson, Vogel and Laurent (2016) suggest that internet-mediated research methods can provide access to diverse sections of the general population. As such, recruitment for all studies will use online sampling with recruitment taking place through the online social networking website, Facebook and through the PCOS charity website 'Verity' (for study one).

Coulson (2015) lists several benefits to conducting research online, including: access to participants, access to hard-to-reach populations, reduced costs, researcher anonymity, flexibility and convenience and access to individuals with stigmatised identities. Similarly, Hewson (2003) details the potential to access large samples of specific populations and the minimal costs involved in online research, as a benefit of internet mediated research. Coulson (2015), however, also identifies several challenges when collecting data online which are applicable to the research within this thesis. One such challenge is 'representativeness' (Coulson, 2015, p.14), that is, that participants recruited online may not be representative of a target population due to the lack of equal distribution of the internet across the population. Indeed, Hewson (2003) also raises the question of biased samples in online research and suggests that online samples are biased but that this may change as the internet grows. Indeed,

more recently Hewson et al. (2016) suggest that whilst ‘in the early days of internet mediated research...there were widespread concerns about biases inherent in the internet-user population’ (p.71) there is no longer bias towards particular groups of users (white, upper middle class, well-educated males). Furthermore, in a comparison of data collected online and via traditional methods (pen and paper), Gosling, Vazire, Srivastava and John (2004) found that their internet findings were consistent with the findings from traditional methods, suggesting that the impact of online vs traditional samples on findings may be minimal. Moreover, Hewson (2003) suggests that online samples may actually be more representative than those that utilise traditional methods.

In 2015, 86% of adults in the UK had used the internet in the preceding 3 months and only 11% of adults had never used the internet (ONS, 2015). Furthermore, the social networking website, Facebook, reports over one billion daily active users as of September 2015 with 894 million of those individuals accessing Facebook through a mobile device (Facebook, 2015). In addition, as of 2012, there were approximately 33 million Facebook users in the UK, more than any other country in Europe (Internet World Stats, 2014), suggesting that over half the UK population (63.7 million) in that year (ONS, 2013) was using Facebook. Considering these figures, and the many ways in which individuals can access the internet (computer, mobile phone, tablet), they provide support for the ‘increasing diversity and inclusiveness within the internet user population’ and samples accessed via the internet (Hewson et al., 2016, p. 77).

Hewson et al. (2016) claim that there is a lack of research on the relationship of different recruitment strategies in internet mediated research and how this may influence the sample. Although they do suggest that recruiting from a special interest group, such as a group dedicated to women with PCOS, will generate a different sample to recruiting in a general group (such as group for buying and selling). Indeed, a search conducted in Facebook (2015) for the term PCOS, revealed 93 closed groups dedicated to women with PCOS (identified through the group name and description); of these, seven groups were specifically dedicated to women with PCOS in the UK. Member numbers, at the time of writing, within the 93 PCOS groups ranged from 23,793 members to the smallest group with 33 members.

Coulson (2015) also suggests that of those individuals who can access the internet, there may be sampling error as not everyone has an equal chance of seeing the recruitment post due holidays etc. To combat this, each day, the recruitment post for Chapters Four to Seven, was

re-posted, or commented on, to ensure that the post remained at the top of the group Facebook 'wall' and therefore visible to as many members of the group as possible throughout the duration of recruitment, in agreement with the group moderators. For the study detailed in Chapter Three, as participants were recruited via Verity, the recruitment post remained in the same position and visible at all times until after the completion of data collection.

2.9 Summary

This thesis aims to further understanding of the impact of PCOS on quality of life for women in the UK. In addition, it aims to measure this phenomena and increase quality of life for these women. This chapter has provided a detailed discussion on the theoretical framework within which this research sits, the methods of data collection and generation that were employed and also the methods of analysis that were necessary to complete coherent research in order to meet the research aims and individual objectives of this research (Braun & Clarke, 2006; Chamberlain, 2015).

Chapter Three -A snapshot of the lives of women with Polycystic Ovary Syndrome (PCOS): A photovoice investigation.

This chapter will investigate and identify how women with PCOS in the UK perceive and define their quality of life. Furthermore, it will investigate how women with PCOS perceive the impact of PCOS on their quality of life, from their perspective. This chapter also restates the methods and methodology used to meet these research aims, and also discusses the findings and their relationship to previous research.

3. 1 Introduction

The clinical characteristics of PCOS include hyperandrogenism, chronic anovulation, insulin resistance and infertility (Archer & Chang, 2004). These can often manifest as hirsutism, obesity (Eggers & Kirchengast, 2001) and acne (Archer & Chang, 2004). PCOS has been found to have a greater impact on women's psychological well-being than illnesses such as asthma, epilepsy, back pain and arthritis but a similar or milder physical impact than these conditions (Coffey, Bano & Mason, 2006). Consequently, Coffey et al. (2006) argue that PCOS affects women psychologically more than physically. Lowenstein (2006) similarly proposes that patients with PCOS are often negatively affected by some of the symptoms they experience, including acne, hirsutism, alopecia and obesity.

Studies show that women with PCOS have an increased prevalence of psychological morbidity (Cipkala-Gaffin, Talbott, Song, Bromberger & Wilson, 2012; Deeks, Gibson-Helm, Paul & Teede, 2011; McCook et al., 2005) and an impaired quality of life compared to women without PCOS (Ching, Burke & Stuckey, 2007; Coffey & Mason, 2003). This suggests that PCOS, and its symptoms, can have a considerable negative impact on women with the condition. Quantitative studies have demonstrated that PCOS has a negative impact on quality of life (Elsenbruch et al., 2003; Upadhyia & Trent, 2007), even when compared with other long-term conditions such as diabetes and coronary heart disease (Coffey et al., 2006).

Qualitative studies exploring the impact of PCOS on quality of life, however, are severely lacking and often limited to clinical settings (Crete & Adamshick, 2011; Percy, Gibbs, Potter & Boardman, 2009; Snyder, 2006). To date the only paper which explores the experience of PCOS outside of a clinical setting in the UK was published by Kitzinger & Willmott (2002);

they found that the women with the condition felt stigmatised and abnormal. Indeed, Liang et al. (2013) claim that understanding the concerns and expectations of women with PCOS is important and quantitative methods fail to provide the necessary information. They argue that the use of qualitative methods, therefore, become increasingly important to understand the meanings experienced by women with PCOS. There is, therefore, a need for qualitative research that explores how women with PCOS in the UK define and perceive their quality of life; and also how women with PCOS experience this condition and perceive the impact of PCOS on their quality of life.

3.2 Photovoice

Photovoice, developed by Wang and Burris (1994), is a data collection method that is being increasingly used in psychological research; particularly to capture an individual's experience of health (Topcu, 2015). It is a process which entrusts cameras in to the hands of people to enable them to act as recorders (Wang & Burris, 1997). Photovoice has been employed to explore a variety of health conditions including; long-term mental illness (Thompson et al., 2008), alcohol and drug education (Sharma, 2010), chronic pain (Baker & Wang, 2006), Alzheimer's disease (Wiersma, 2011), food allergy (Valentine & Knibb, 2011) and many more (Booth & Booth, 2003; Duffy, 2010; Fitzpatrick et al., 2012; Vaughn, Rojas-Guyler & Howell, 2008; Wang & Pies, 2004). It has been suggested that photovoice is able to uncover rich descriptive information and can be widely adapted to fit the needs of research (Catalani & Minkler, 2010). In the case of this study, photovoice would allow participants to generate data free from the researcher's input, thus enabling them to reflect their perception of quality of life, rather than any pre-existing concept.

Wang and Burris (1997) claim that photovoice can be a powerful research method when employed with stigmatised or ostracised groups of people and, furthermore, they suggest that research participants often have the experience and insight into their condition which professionals and outsiders lack. Wang (1999) maintains that photovoice allows people with cameras to photograph their perceived health realities. Consequently, Ruby (1991) states that photovoice enables health researchers to gain a different perspective of the world. Wang and Burris also claim that photovoice enables participants to record things relevant to their life such as settings or ideas which health professionals and researchers may not have previously had access too. Additionally, Brunsdon and Goatcher (2007) suggest visual images allow

people to record their experiences and feelings more effectively than words alone allowing them to think about their lives in ways not previously considered.

Brunsdon and Goatcher (2007) maintain that in any image there is a range of data, both observable and interpretable. They state that people inhabit a visual world and experience life as visual encounters. Accordingly, photovoice engages participants in the production of new images; this puts the participant and the image they create at the centre of the research (Brunsdon & Goatcher). Moreover, Foster-Fishman, Nowell, Deacon, Niever and McCann (2005) propose that photovoice not only allows for participants deep reflection on their lives and experiences, but also empowers participants and creates a safe climate for the exploration of diverse perspectives.

Photovoice, therefore, may offer new insights into the impact that PCOS can have on an individual's quality of life and allow them to demonstrate how they perceive their quality of life to be impacted. It may also help further understanding of the condition by providing a snapshot of the day-to-day life of women living with this condition. As such, this study aims to utilise a photovoice methodology to enable women with PCOS to illustrate their own perceptions of quality of life and what this term means to them, and also to explore the impact of PCOS, on quality of life from their perception.

3.3 Method

3.3.1 Participants

Participants were recruited via a post on the website of a popular PCOS charity network named Verity (Appendix A). According to Wang (1999) participants recruited for a photovoice study may be selected according to a specific sampling criterion. Therefore, the inclusion criteria for this study were: Participants aged 18 and over, lived in the UK and experienced symptoms of PCOS. The invite to participate specified that participants would be excluded if they experienced any other long-term or mental illness which was not related to PCOS. Upon contact to the researcher participants were asked to confirm that they met the inclusion criteria. Thirty-four participants agreed to participate in the photovoice study and were sent a study pack, nine study packs were returned. Of those reported, age ranged from 20 to 45 years old ($M_{age} = 31.5$ years) and length of time since diagnosis ranged from one to three years ($M = 1.8$ years). Current prescribed medications taken by participants included the Oral Contraceptive Pill ($n=3$), Cyproterone, a hormonal treatment ($n=1$), Metenamic Acid, a

pain killer (n=1) and Metformin, an anti-diabetic drug (n=1). Supplemental treatments used by the women in this study included Vitamin B (n=1) and Valerian Root tablets (n=1).

3.3.2 Materials

A study pack which contained a disposable 27 exposure camera, an A7 notebook containing plain paper, a consent form (Appendix B) and a letter of instructions (Appendix C) was sent to participants. The letter of instructions directed participants to fill out the consent form and to return it with their study pack; it also reiterated the contact details of the researcher. An envelope and an in depth information sheet (Appendix D) were also sent by first class post to participants. The information sheet included information such as: the purpose of the study, what taking part involved, how their data would be stored and guidelines on what to photograph, for example no inappropriate images. Return postage and a pre-printed return address on a sticky label were also included in the study packs.

The majority of previous photovoice research in health has used disposable cameras (Aubeeluck & Buchanan, 2006; Baker & Wang, 2006; Moffitt & Vollman, 2004; Thompson et al., 2008; Valentine & Knibb, 2011; Wang & Pies, 2004; Wiersma, 2011) due to their ease and cost effectiveness. However, the choice of a disposable camera was also guided by the researcher's preference (Wang, 1999) as it allows for images to maintain a consistent size and format, and it allowed for ease of use by the participants.

3.3.3 Procedure

In previous photovoice research after the photographs have been developed, researchers conduct an interview with the participants about the images produced. However, as Brunsten and Goatcher (2007) state, interviews can follow the researcher's agenda. Wang (1999) suggests that researchers may tailor photovoice, as long as the application of photovoice is characterised by a three stage process of selecting, contextualising and codifying.

The present study asked participants to write in notebooks and make diary entries in order to limit potential researcher bias. Researcher bias is apparent in traditional qualitative data collection methods such as interviewing, as the researcher becomes the instrument through which data is collected (Poggenpoel & Myburgh, 2003). Poggenpoel & Myburgh (2003) suggest that this can lead to researcher bias particularly if the researcher is a member of the population under study. However, the use of notebooks allowed for the data to be

contextualised by the participant and allowed the participant to highlight the information they felt was important, rather than answering questions at the request of the researcher which may have presented a second-hand account of the participant's reality (Merriam & Tisdell, 2016). As Wang and Burris (1997) state "what researchers think is important may neglect what the community thinks is important" (p.372). Notebooks, therefore, allowed for data collection to take place with minimal guidance or interference from the researcher.

Participants were sent study packs via the postal system. Participants were instructed that they had one week to take any photograph they wished. This time frame allowed the participants to record a detailed account of their daily activities over a short period of time (Milligan, Bingley & Gattrell, 2005). Participants were also told that there were no right or wrong answers. Participants were not given any instruction on how to use the camera or what to take pictures of, besides the research overview to explore impact of PCOS on quality of life. Participants were also asked to write a diary entry for each photograph taken in the A7 notebook. Again, participants were not given any instruction on what to write in the diary besides being told that the purpose of the diary was to put the photograph just taken into context and to tell the researcher more about it. This allowed for a minimum of interference on behalf of the researcher (Catalani & Minkler, 2010).

Participants were informed that should they not use all 27 exposures of the camera within the given week then they were to still send the camera back with the study pack. Participants were also informed that they should send the consent form back with the disposable camera and the A7 notebook. Participants were then required to return the study pack, excluding the letter to participants and information sheet. All participants were sent a reminder email to send the camera back approximately two months after the first study pack was posted. Upon receiving the returned study pack, disposable cameras were developed and diary entries were transcribed.

3.3.4 Ethics

Research complied with The British Psychological Society's ethical guidelines (2009, 2010) and ethical approval was obtained from the Psychology Research Ethics Committee at the University of Derby (Ethics Approval Number: 050-11-SW, see Appendix F).

Participants were required to give informed consent. Participants were asked for consent to use verbatim quotes from diary entries and they were aware that they would remain anonymous. Participants were also reminded of their right to withdraw from the research at any time up to three weeks after taking part, without giving a reason for doing so.

Participants were also informed that, should they wish to take any photographs of people, they were to gain fully informed verbal consent first. They were also informed that should they take any photographs of people, they would not be republished and would only be used for analysis which would be detailed in the researcher's thesis, to ensure anonymity of those being photographed.

3.3.5 Analysis

The diaries were analysed using an inductive thematic analysis (Braun & Clarke, 2006) and followed the six steps recommended by Braun and Clarke (2006): familiarization with the data, generation of initial codes, searching for themes, reviewing themes, defining and naming themes, and writing the final report. The analysis was primarily undertaken by one author. The final themes were reviewed by all authors alongside diary entries and photographs to ensure that all were in agreement that the themes were an accurate representation of the data, and that there was not too much overlap between themes (Braun & Clarke).

3.4 Findings

The participants in this study experienced a variety of PCOS symptoms including hirsutism, obesity, acne, alopecia, irregular or disrupted menstruation, miscarriage and infertility. The number of diary entries participants made were varied as were the length of entries. However, despite the length or amount, the data was rich enough to provide an opportunity to explore how women with PCOS perceive their condition and how it impacts their quality of life. Three major themes emerged from the data: Control, (sub-themes Symptom Management and PCOS as Controlling) Perception, (sub-themes Feminine Identity and Positive Outlook) and Support, (sub-themes The Health Care System, Education and Relationships). Quotes displayed are reproduced as written in the participant's diaries and accompanied with the participant's pseudonym and age (age unavailable (AU)).

3.4.1 CONTROL

3.4.1.1 Symptom Management

The theme *Symptom Management* was discussed by all of the participants in this study. It was also the subject of many photographs. Clark et al. (1991) define self-management as the ‘day to day tasks’ that a person must complete to control the impact of their condition (p.5) reflecting this theme title and its contents. Certainly, many participants had protocols in place to help them control their PCOS symptoms, including: hair management routines to control hirsutism, daily skin routines to control acne, specific hair washing routines to control alopecia and dietary plans and/or exercise to try and control their weight. These are similar to those procedures used by individuals to control ongoing illness outlined by Leventhal et al. (2003), including: taking dietary supplements; prescribed medications, and over the counter medications.

Crete and Adamshick (2011) also reported a similar theme, ‘Gaining Control’, after interviewing women with PCOS. They suggest that the women in their study also sought to gain control of their PCOS, including their symptoms. They advise that the primary importance for their participants was to gain control of their symptoms, through self-treatment of symptoms such as hirsutism, acne and through weight control. Castillo (2008) also reported the theme ‘Lack of Control over Syndrome and its Symptoms’ in their qualitative research. Castillo proposes that the participants in her study experienced feelings of losing control over their bodies and their condition. Finally, Snyder (2006) also reported a theme of ‘gaining control’ when conducting semi structured interviews with women with PCOS.

The quote below reveals how the symptom of hirsutism can impact on women with PCOS and their daily lives. In this quote Sandra describes how she spends time using hair removal methods, in this case using tweezers to pluck hair, in order to stay in control of her facial hair. She further demonstrates how this is a continued process which takes place daily, if not more frequently by stating that ‘Its neverending.’ Sandra also discusses how the preoccupation with her facial hair continues throughout the day, despite the situation, be it ‘at work, at home, with friends’. This preoccupation with facial hair is present throughout her daily activities. She furthers this by claiming that if she were to find a hair, she ‘cannot rest until its gone’, further demonstrating how facial hair and the need to stay in control of it, can infiltrate and impact on every aspect of her day. Similar findings were reported by Lipton, Sherr,

Elford, Rustin and Clayton (2006) who found that more than a quarter of the participants in their study (n=80), which explored the impact of living with facial hair, stated that their facial hair was constantly on their mind and 67% of the participants reported checking for hairs in the mirror and by touch.

I've now spent a good 10 minutes finding new hairs on my chin. I pluck it every single day – probably 10-15 hours a day – really thick stubborn black ones. Its neverending. I spend a lot of time feeling my chin – at work, at home, with friends. When I feel one that needs plucked I cannot rest until its gone. I get a really stubborn one on my shoulder too. Just the one but it bothers me SO much that if I can't pluck it myself I have to get someone else to do it. [Sandra,

31]

Similarly to the quote above where Sandra says 'When I feel one', Kitzinger and Willmott (2002) also found that participants with PCOS who took part in their study often mentioned the way hairs felt. Sandra also accompanied the above quote with a photograph (shown below) of a pair of tweezers.



Figure 3.1 A pair of tweezers taken by Sandra

The daily commitment to removing hair displayed in the quote above by Sandra is also shown in the quote below by Linda who says that she has to go through a process of hair removal 'everyday'. Moreover, by using the word 'have', Linda demonstrates that this routine is something which she is compelled to do. She describes how she uses razors and tweezers to remove hairs from not only her face but also the rest of her body. Similarly, Snyder (2006) reports that all the participants of their research invested time and money in treatments in order to control their hirsutism. This included methods such as waxing, shaving and plucking with tweezers.

Lipton et al. (2006) also report that almost 40% of the women with PCOS in their study reported using one of more methods of hair removal and over half of the participants reported putting a lot of effort into facial hair removal. Moreover, Oláh (2004) states that cosmetic procedures play an important role in managing hirsutism. Weiss and Bulmer (2011) also report that participants used various methods of hair removal to cope with symptoms. In Linda's diary entry (below) she lists the places on her body where she has to remove hair from; interestingly however, she chooses to list the areas of her body in a top to bottom list rather than in sentence formation, perhaps to further illustrate the extent of her hair growth.

every day I have to get rid of some hair from my body – which is every where-

back

tummy

legs-toes

face

hands-fingers

arms

chin

neck

up my nose.

I use a razor for women, an electric shaver for women and tweezers, I use on my face, neck, tummy. [Linda, 45]

In the photo below Linda (quoted above, as written in diary) shows the different systems of hair removal that she uses on a regular basis, including two different types of razor and a pair of tweezers (as detailed in the quote above).



Figure 3.2 A pair of tweezers and two hair removal devices taken by Linda.

Similarly to the quote from Linda, Amy demonstrates (in the quote below) how managing her symptoms of hirsutism take up her time and energy. She shows that dealing with facial hair to her ‘is like a chore’, suggesting that this is a daily, monotonous routine. Moreover, she claims that this is something you ‘HAVE’ to do and is not down to choice or eagerness. This is reflective of the theme control and how participants in this research felt that they had to use hair removal procedures to control their hirsute symptoms of PCOS.

Having to cope with facial hair is like a chore, something you do not WANT to do, but something you HAVE to do! [Amy, AU]

Washington (2005) states that participants in their qualitative study reported removal of their unwanted hair through similar processes as the participants in this study, including methods such as shaving, plucking and waxing. In the photo below Amy shows herself having her legs waxed in order to help manage the PCOS symptom of hirsutism. Her accompanying diary entry (below) describes how she allocates time and money to this and how, although she deems waxing ‘expensive’, she feels it is ‘necessary’.

Ever since the age of 10, I have been getting my legs waxed. I usually have to consider getting them waxed every 2 months or so. Although this is an expensive means of eradicating the hair from my legs, I find that it is very much necessary. Since I have been getting them waxed my dark, thick hairs have thinned out a lot. [Amy, AU]



Figure 3.3 Getting her legs waxed, taken by Amy.

Research has found that women with PCOS who suffer from symptoms of hirsutism may experience negative feelings of well-being (Archer & Chang, 2004). Moreover, quantitative research by Guyatt, Weaver, Cronin, Dooley and Azziz (2004) proposes that excessive hair growth in women with PCOS can have a negative impact on their quality of life. Correspondingly, this research has qualitatively demonstrated how suffering from hirsutism can impact women with PCOS in a negative way. It has, however, expanded on the understanding of what it is like to live with, and experience, the symptoms of hirsutism whilst suffering with PCOS.

Janssen, Hahn, Tan, Benson and Elsenbruch reported in 2008 that obesity and hirsutism were associated with negative aspects of quality of life. Accordingly, *symptom management* was also discussed by participants in terms of weight maintenance and loss. Participants took photographs of food, scales and themselves to demonstrate how PCOS, and the associated

weight issues, impacted on their quality of life. They also referred to exercising in their diaries, as another means to stay in control of their PCOS. Quantitative research has suggested that weight gain has the greatest negative influence on health-related quality of life in women with PCOS (Jones, Hall, Balen & Ledger, 2008).

In the quote below Stephanie explains that she invests ‘time and energy’ into controlling her eating habits, further suggesting that women with PCOS have to be constantly vigilant with their diet and nutrition in order to maintain control over their PCOS and in particular the symptoms relating to weight gain and obesity.

I spend so much time and energy trying to control my eating in this sea of demands which pull me in different directions. [Stephanie, AU]

Amy photographed the food she eats in order to control her weight (below). She also discusses, in the quote below, how she attempted to manage her symptoms through diet and exercise. In the quote below she describes how she has improved her diet and how she exercises regularly in order to maintain control over her weight.

This has led me to take on a fruit and veg diet and very few carbohydrate type foods. Unfortunately my diet still consists of rather a lot of carbohydrate because that is my staple food. But, I manage to outweigh the amount I eat through exercising at least 3 times a week.... Thanks to exercising and a better diet, I have managed to lose weight [Amy, AU]



Figure 3.4 A photograph of food, taken by Amy.



Figure 3.5 A photograph of food, taken by Sara.

Sara also decided to photograph food. In this case she photographed bread loaves (above) and made a diary entry about food and how she tries to keep carbohydrates to a minimum in order to lose weight, she writes:

This represents carbs in general. I know they are an issue & try to keep them to a minimum but it doesn't help my weight. [Sara, AU]

In the quote below Denise also demonstrates how women with PCOS aim to control their PCOS symptoms through weight loss.

A lot of my time and energy goes on thinking about food and diet. [Denise, 30]

Both Stephanie and Denise use the phrase 'time and energy', demonstrating the extent that trying to control their diet and food consumption can infiltrate their daily lives. Similarly, de Ridder (2004) suggests that self-care routines in long-term conditions can be a burden on the individual due to the responsibility of performing daily tasks associated with managing their condition.

One method participants developed in order to keep track of and control their symptoms, especially in relation to diet and food consumption was to create food diaries or diet sheets. The picture below shows a diet sheet which Denise had stuck to her fridge. By placing this diet sheet on her fridge it shows her daily commitment to controlling her weight through an 'eating plan'.



Figure 3.6 Diet sheet, taken by Denise.

Denise also used a notebook to keep track of her menstruation, which she photographed (below). In the accompanying diary entry she writes:

Notebook with cycle tracking – while trying to get pregnant I became obsessed with my cycle. Every twinge or physical change was noted and analysed. I get annoyed trying to work out if I am having a long cycle or if I am pregnant. I do usually get bad PMT (eg moody, hungry, tired, lethargic, headaches) so if I don't have these signs then I get hopeful that I might be pregnant. I wish I could just relax but it is really hard to forget about it. [Denise, 30]

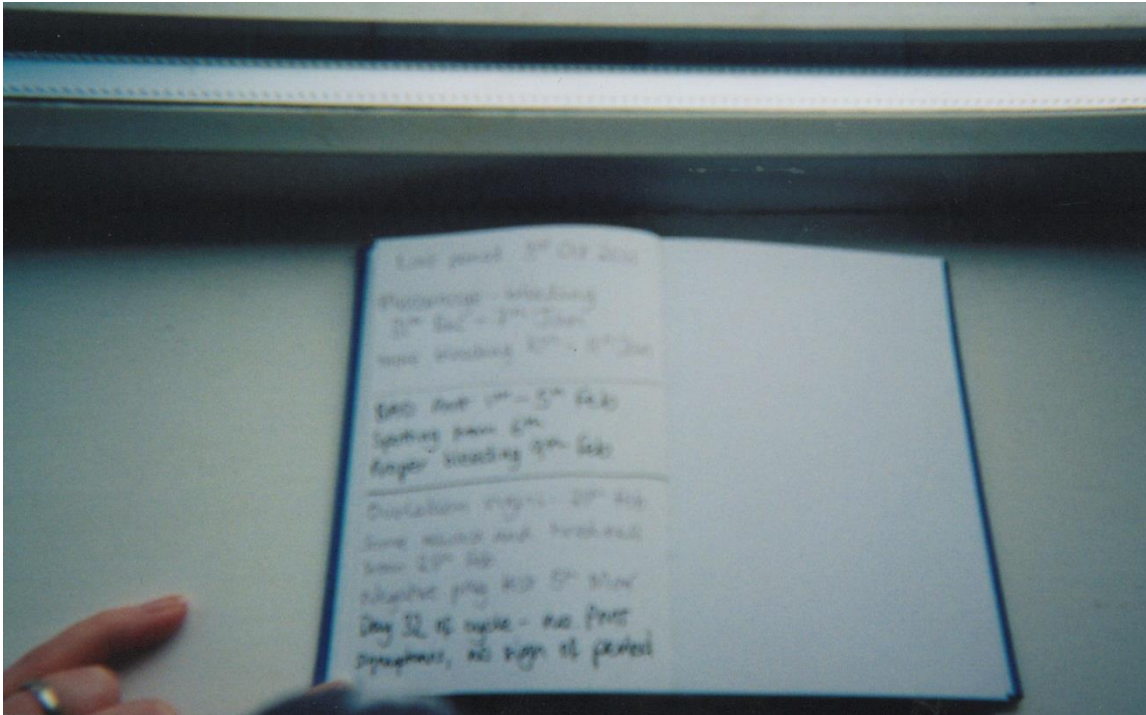


Figure 3.7 Menstruation diary, taken by Denise.

Similarly, Stephanie writes below about how she keeps track of her symptoms through the use of mobile phone applications and personalised tracker documents. She states that keeping a record of this helps her feel more in control of her body and her PCOS symptoms.

Keeping track of ..bodily functions (fertility, sleep, eating) using tracker sheets and apps on my phone helps me to feel .. less like my body is unpredictable/ out of control. [Stephanie, AU]

Another form of managing symptoms mentioned by one participant included a 'daily skin routine'. Jessica described in her diary (the quote below) how she managed her acne symptoms through using various face washes and creams, often combined with medications. Research suggests that acne is frequently seen in women with PCOS (Hill, 2003) and that in some cases, it may be the only clinical manifestation of PCOS (Bunker et al., 1989).

This picture shows my daily skin/morning routine. It starts off in the shower with a face wash applied with an exfoliating glove to clean the skin. I don't use soap only infacare (childrens wash) on my skin as its very prone to spots/blackheads and anything scented makes it a bit grubby. I then (after drying off) put on a blackhead clenser. I apply Nivea as its quite thick...I

then put on “wake me up anti fatigue effect and radiant glow concealer to my biggest spots/redest areas that are around the nose, chin and more recently neck. [Jessica, 20]

In the quote above Jessica describes her daily skin routine including what products she uses, when she uses them and how she uses them. Similarly, Castillo (2008) found that women with PCOS in her study also used cosmetic products to control their acne and hirsutism symptoms. The photograph below taken by Jessica shows the products that she uses every day in order to maintain some control over her acne. It also shows various medications that Jessica takes to control her PCOS.

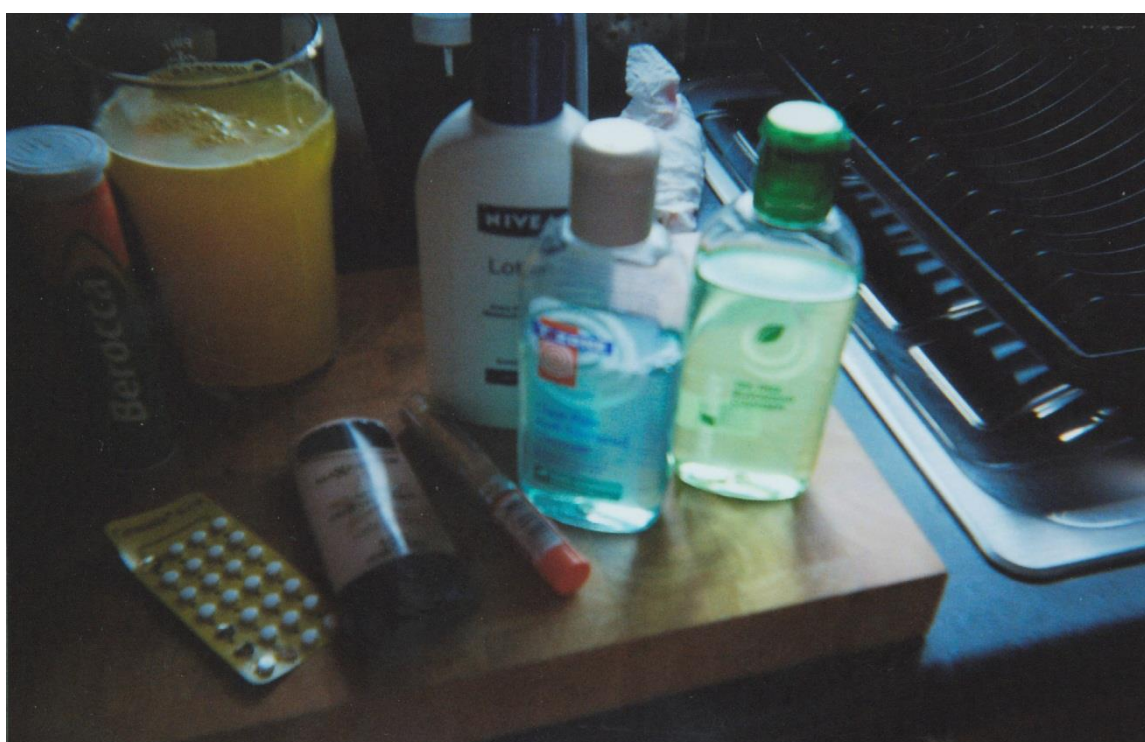


Figure 3.8 Medications and acne treatments, taken by Jessica.

Other participants also regularly took medication to control their symptoms, Amy writes:

I took an image of the pills I have to take to avoid as many PCOS symptoms as is possible.

[Amy, AU]

Medications and packets of tablets were common subjects of photographs, with six participants out of nine taking photographs (which developed) of them. Snyder (2006) similarly found that some of the women in their study took medications to help manage their

acne symptoms. Similarly, Leventhal et al. (2003) proposed that in order to control long-term illness individuals would take dietary supplements, prescribed medications and over the counter medications. Photographs of the medications taken by participants on a daily basis to try and control their PCOS symptoms are shown in the photographs below. Interestingly, each participant decided to take the photograph in a similar manner, with the tablet packet out of the box and placed on a plain surface. Each participant also photographed the tablets with space around the packet.



Figure 3.9 A photograph of the contraceptive pill, taken by Amy.



Figure 3.10 A photograph of the contraceptive pill, taken by Sara.



Figure 3.11 A photograph of the contraceptive pill, taken by Sandra.

Quantitative research by Hahn et al. (2005) suggests that obesity, hirsutism and acne are all clinical variables which contribute to psychological problems in women with PCOS.

This qualitative research may expand and add to the understanding of what it is like to live with PCOS and how many women try to gain control over their symptoms through a combination of self-management methods. Moreover, it demonstrates how, for women with PCOS, this daily fight for control over symptoms can be time consuming, expensive and often unsatisfactory. De Ridder (2004) suggests that controllability of a condition is a key factor which influences how individuals experience their long-term conditions. Indeed, Helgeson (1992) suggests that perceived control of a long-term condition is a strong predictor of adjustment to the condition.

The self-management routines identified by the women in this study are similar to those experienced by individuals with other long-term conditions. De Ridder (2004), as identified by some participants in this theme, proposes that self-management routines that individuals employ to control their long-term condition can be a burden due to the daily tasks related to self-management.

3.4.1.2 PCOS as Controlling

Another subtheme that emerged from the diary entries was *PCOS as Controlling*. Castillo (2008) also discovered that women with PCOS in their study felt a lack of control of their PCOS and its symptoms. Moreover, Castillo's participants suggested that not being in control of their lives was unfair. This is demonstrated in the quote below by Lucy who is discussing her diet. She describes how she is unable to eat ready-made food in order to prevent her symptoms worsening and pain developing. She also explains that she no longer gets to take part in activities she enjoys, in this case baking, because she cannot eat anything she bakes.

Ready made stuff is nono, I can literally feel my ovaries stinging in the hours after I have ready made stuff. It sucks. For the record, I was epic at baking before I was diagnosed. Don't get to anymore, really. [Lucy, AU]

Similarly, in the quote below participant Helen explains how because of her condition, and her hirsutism symptoms, she keeps other people, particularly men, at a distance. Similarly Percy et al. (2009) stated that the women in their qualitative research reported feelings of isolation. Washington (2005) also discovered that the women with PCOS in their study

avoided interacting with people because of their PCOS symptoms leading them to become isolated.

Being a woman, your face is very important to you. It's the first thing someone sees. I have been suffering with PCOS for 5 years (only recently diagnosed) 5 years of excess hair, 5 years single. Because of this I do not let men or anyone else close to me. [Helen, AU]

Research by Keegan, Liao and Boyle (2003) has similarly suggested that many women with PCOS who experienced the symptoms of hirsutism avoided activities. In addition Barth, Catalan, Cherry and Day (1993) also found that participants with hirsutism avoided social situations.

Snyder (2006) found that the women with PCOS in their study were also concerned with their lack of control over their ability to become pregnant. Moreover, their participants described how it made them feel out of control. Similarly, in this research Jessica explains how she feels under pressure to become pregnant. She writes that becoming pregnant for her is like 'a ticking time bomb', demonstrating the urgency of becoming pregnant for her and the finality she perceives if she does not become pregnant by 'the age of 25'.

However I also see it as a ticking time bomb. And if I don't get pregnant from the age of 25. THAT IS IT. [Jessica, 20]

The sense of pressure and urgency demonstrated by Jessica may be reflective of the PCOS symptom of infertility which many women with PCOS can experience (Balen & Rutherford, 2007). There may be a number of reasons why women with PCOS feel pressured to conceive. Fertility declines with age (Dolan & Rudisill, 2015), and women in the UK are only eligible for in vitro fertilisation (IVF) treatment up to the maximum age of 43, dependent on the local area (NICE, 2013; NHS, 2016) and after trying to conceive for two years (NICE). Those women not eligible for treatment, due to the area or age, may pay for private IVF treatment, however this is expensive at £5000 per treatment (NHS, 2016). In addition, a successful treatment outcome is reduced in women with a higher BMI (NICE, 2013). As such, women with PCOS may feel a sense of pressure to conceive whilst young due to the impact of PCOS on their fertility, the difficulty maintaining a low BMI because of their PCOS symptoms

(Balen & Rutherford), the time needed for trying to conceive and then subsequent treatments and also due to the limited resources available to help women in the UK conceive.

Another way in which PCOS could be seen as controlling is through the life changes women with PCOS have to make due to the condition for example, in the quote below Lucy describes how she is coming to terms with the condition and how she feels having PCOS may impact her life in the future.

I have friends who are getting married soon, and it's starting to dawn on me that I might have to take a path in my adult life different to the family/kids plan the rest of my friends are keen on. I was allergic to the birth control that let me have normal sex drive, and for pretty obvious reasons I'm not holding out on having kids. I'm scared that in the next few years I'll become pretty isolated as my friends pair up and go through things I can't relate to. [Lucy, AU]

The quote above shows how when a woman is diagnosed with PCOS it can be controlling. Not only do women with PCOS have to come to terms with the impact of PCOS on their fertility but also how their future plans and life may change due to the condition. This change in an individual's thoughts or future plans has not previously been discussed in the published PCOS literature however it is important for health professionals who work with women with PCOS to recognise this in order to fully support them.

Lucy (in the quote above) also discusses the impact of PCOS on her friendships and expresses concern over becoming socially isolated in the future, similarly to the quote displayed earlier by Helen. In the quote below, Stephanie also describes how she has become and continues to become isolated from friends. She explains that relationships are 'complicated' to her as the symptoms of PCOS can change the accepted expectations of relationships such as having children.

In part that's because the symptoms of PCOS make me feel undesirable and also because it makes all the taken-for-granted expectations of relationships (settling down and having kids gets all the more complicated)Because relationships seem so complicated to me, spending time around couples can make me feel quite jealous. Also as my friends become increasingly settled into family lives I become increasingly removed/different from them. [Lucy, AU]

Once again, we see in the quote above how having PCOS can alienate women from their social groups due to their PCOS symptoms, such as infertility and in this way PCOS could be seen as controlling for the women who experience it.

3.4.2 PERCEPTION

3.4.2.1 Feminine Identity

The theme *Feminine Identity* has previously been discussed in the published literature. Most notably by Kitzinger and Willmott (2002) who explored the experience of PCOS from a feminist perspective. One of their main conclusions was that women with PCOS felt challenged in their perception of self as feminine. Moreover, they felt that women with PCOS perceive themselves as further away from the ‘feminine’ ideal.

In the quote below Linda describes how having symptoms of PCOS such as irregular periods, hirsutism and carrying excess weight make her feel like she is ‘not a woman’. She furthers this by referring to her weight, and in particular her stomach, as being like a ‘man’s beer belly’. Participants in Kitzinger and Willmott’s (2002) research also indicated that they felt like they were not a ‘normal’ or ‘proper’ woman. Their participants also often described their excess hair symptoms using male terminology. Similarly, in the quote below, Linda uses male terminology to describe how they feel about their excess weight. Masculine language or references are also used throughout the participant’s diaries either through referring to themselves or to their symptoms. For example ‘shaving of the moustache’, ‘I’m rocking the 5 O’Clock shadow tonight’ and ‘Got a nice bit of stubble going on now’.

Makes me feel im not a woman scribble – no periods – which makes me wonder what is happening inside of me – hairy – scribble fat around the middle like a man’s beer belly even though I go gym or swimming every week [Linda, 45]

Helen, in the quote below, also compared the excess hair growth she experiences as a result of her PCOS to that of a man.

Especially my face. It’s embarrassing, uncomfortable, no woman wants hair on their face especially long & thick like a mans. [Helen, AU]

Similarly to these findings, Snyder (2006) found that women with PCOS in their study expressed how symptoms, primarily hirsutism, impacted on their feelings of themselves as female, one participant in their study states ‘You’re feeling not as womanly’ (p.388). Additionally, research by Keegan et al. (2003) also found that women with PCOS who suffered with hirsutism felt unfeminine. Several of the participants in this study also referred to their femininity, or lack of it. For example, in the quote below by Amy, she states that she feels ‘less female’ because of her hirsutism symptoms. Moreover, she explains how this is a regular occurrence for her and it impacts on her mood and self-esteem.

Today, I feel quite self-conscious and less female than usual because of my facial hair growth. I often have days like these and it really gets me down [Amy, AU]

Landmark and Wall (2002) suggest that in women who have undergone a mastectomy due to cancer, loss of a breast due to cancer could result in a loss of femininity. Similarly, Helms, O’Hea and Corso (2008) suggest that as women with breast cancer face weight gain, hair loss (both also similar symptoms to PCOS) and loss of a breast(s), they may not meet society’s ideals of what a woman should look like, and consequently may not feel feminine after treatment. In a study exploring body image in the first months after treatment for breast cancer in young women, Fobair et al. (2006) found that women felt less feminine (7%). Similarly, the women with PCOS in Kitzinger and Willmott’s study (2002) said that they felt unfeminine due to their irregular periods caused by PCOS. This is similar to participants in this study who felt less feminine due to their PCOS and its impact on their ability to meet the ‘typical’ role of a woman. This is demonstrated in the quote below by Jessica who discusses the impact of PCOS on her perception of self as a woman in regards to her ability to conceive.

When it does I feel like frag-ments of a woman. Like I have the body, the bits but they just don’t work. [Jessica, 20]

By using the term ‘frag-ments of a woman’ and also by claiming that her body does not ‘work’, Jessica compares herself to something that is broken. Similarly, Denise discussed how she takes Valerian Root tablets, described to her as a ‘natural sedative’, after recently experiencing a miscarriage, to help her sleep, instead of thinking about the impact PCOS has had on her ability to carry a child.

Since I had a miscarriage 2 months ago they have helped me to sleep rather than lie awake wondering if my deficient womb will ever carry a child. [Denise, 30]

Similarly to the quote from Jessica, it appears that women with PCOS may perceive themselves as being broken or as lacking something. She writes that her womb is ‘deficient’, expanding the perception women with PCOS have of themselves being broken or damaged. Lucy similarly wrote:

Being able to do reasonably well....makes me feel not as useless. I know that’s a strong word, but I’m a girl that doesn’t function as a girl. [Lucy, AU]

In the quote above Lucy also refers to herself as not functioning or working correctly. She adds that being able to do well, in this case she is referring to her work at college, makes her feel not as ‘useless’, suggesting that the impact of PCOS on the menstrual and reproductive system renders her less valuable or suitable. Likewise, Kitzinger and Willmott (2002) found that the women in their study experienced their menstrual periods as abnormal and that this influenced their sense of self as a woman.

This feeling of being different or abnormal was also mentioned by Amy (in the quote below) when she describes how she feels about taking medication to ‘avoid as many PCOS symptoms as possible’.

This course of action is unnatural for a woman and it gets me down that my body will never naturally produce the right levels of hormones. [Amy, AU]

Once again we see how women with PCOS can perceive themselves as being different from other women. In this case, Amy’s perception is distorted by the very act of taking medication in order to gain control over her hormones and therefore her PCOS. It is seen as abnormal for her to take tablets or medications to achieve what she believes to be natural for a woman to experience, in this case to control her symptoms of hirsutism and weight gain. Qualitative research has similarly revealed that women with PCOS are aware that taking medications to gain control of the menstruation is artificial and as the participant above mentions, unnatural (Kitzinger & Willmott, 2002).

3.4.2.2 *Positive Outlook*

The theme *Positive Outlook* featured in four of the nine participant's photographs or diary entries. Many participants perceived their situation in a positive way; they described how certain situations or behaviours helped them to develop a more positive outlook. Snyder (2006) briefly discusses how a positive outlook was important to some of their participants with PCOS. However, whilst Snyder (2006) has touched upon positivity in her research, the theme *Positive Outlook* has not been discussed in depth by any previous qualitative or quantitative research.

In the quote below Stephanie explains that keeping a 'positive' diary helps her to focus on the positive aspects of her life.

The positive diary my (CBT) counsellor suggested to me last year helps me focus on the positive parts of my life. [Stephanie, AU]

Stephanie also photographed her college card (below) and discussed (in the quote below) how doing everyday activities, such as going to college and interacting with others also helps her to feel positive.

College – interacting with others during break or group work activities helped me feel more positive and centred. [Stephanie, AU]



Figure 3.12 A college ID taken by Stephanie

Similarly, Amy writes in the quote below that swimming helps her to feel that she is ‘combating’ her PCOS and in turn this helps her to feel more positive.

Swimming, somehow, makes me feel as though I am combating my PCOS slightly and this makes me feel quite positive on my outlook. [Amy, AU]

Hefferon and Boniwell (2011) argue that individuals who develop optimism may engage constructive coping such as acceptance and positive reframing. Positive reframing has been reported to be a frequently used coping strategy for people with diabetes (Tuncay, Musabak, Gok & Kutly, 2008). Additionally, Lutgendorf et al. (2002) found that women with gynaecological cancer, who coped using positive reframing, reported better quality of life at one year follow-up than those who did not.

Positivity was also discussed by Denise who had recently suffered a miscarriage. In the quote below she explains how a story in a newspaper about miscarriage had been upsetting for her at first, but it had then given her hope that she would conceive despite having PCOS (photograph below).

Article on miscarriage in today's metro – upset me this morning on first sight but on reflection it is a positive story not to give up hope. [Denise, 30]



Figure 3.13 An article on miscarriage in the newspaper, taken by Denise.

Snyder, Lopez and Pedrotti (2011) suggest that for an individual to continue hoping to achieve a goal, then there must be sufficient value attached to the goal. They add that hope is thought to strengthen goal striving, especially when the goal is at least somewhat in doubt and viewed as very important, such as Denise's desire to conceive with PCOS.

Sara also decided to take a photograph of a baby bottle to represent her 'joy at being able to conceive naturally', she writes:

Baby Bottle – This represents my daughter & the joy at being able to conceive naturally & fairly quickly despite PCOS. [Sara, AU]



Figure 3.14 A toy baby bottle, taken by Sara.

3.4.3 SUPPORT

3.4.3.1 The Health Care System

Frustration with support, or lack of it, from the health care system was mentioned in the diaries by several participants. A number of qualitative studies have previously demonstrated that women with PCOS felt frustrated by, and angry about, the lack of information and support provided by health care professionals (Crete & Adamshick, 2011; Kitzinger & Willmott, 2002; Snyder, 2006; Washington, 2005; Weiss & Bulmer, 2011). The health care system and the support it provides was also discussed by Castillo (2008) who reports that women with PCOS often felt that they were at the mercy of their health care providers and that there was a lack of information available to them at the time of diagnosis.

Snyder (2006) similarly found through an exploration of the lived experience of PCOS that women with PCOS felt frustrated during the diagnosis process. Many of the women in their study felt that the information given by health professionals was inadequate or that the health professionals did not allocate enough time to them at the time of diagnosis. Participants in research by Crete and Adamshick (2011) also expressed frustration at having to see several health care professionals in order to get a diagnosis. Similarly, in the quote below Jessica

describes how she was received by health care professionals when she first approached them about her symptoms. She stresses that she had to ‘push’ to get a diagnosis and regularly ‘visit the doctor’. She goes on to describe how, even after receiving a referral, it took several years for her to get the tests that enabled her to be diagnosed.

The first reaction and advice I got from doctors was that it was probably puberty, the spots were puberty, the migraines and so on. I was also told to go on a diet. I had to push and visit the doctor regularly before even getting referred, and even then it took over 2 years to get any tests other than bloods and iron done. [Jessica, 20]

Crete and Adamshick (2011) also reported that women with PCOS in their research were often frustrated with their interactions with health care providers; this then resulted in a lack of confidence in the health care system. Additionally, participants commented on the lack of attention to them and their symptoms by health care providers and many were exasperated that their treatment was symptom based. This aggravation with symptom based treatment was also expressed by a participant in this study, Lucy writes:

Doctor only really offers to address 1 symptom at a time – it’s like “You can either not look like a monkey under your clothes, or have a greater chance of starting a family later. Pick one. [Lucy, AU]

Frustration with the health care system and health service providers has also been reported by Washington (2005) who explored the effects of PCOS on the daily activities of women in the USA. Washington also found that women with PCOS often expressed frustration with the medical community and that participants experienced symptoms for many years before receiving a diagnosis. Moreover, participants expressed frustration at the lack of knowledge of health care providers, ultimately leading to a lack of trust in the medical community. Similarly, in the quote below, Jessica discusses how health care professionals, including doctors and counsellors, have been unable to answer her questions about the condition.

I wonder if the weight has always been a result of PCOS or if the PCOS was caused by sudden weight loss in my early teens. This is something that no one has been able to answer. Doctors or counsellors that I have been to see. [Jessica, 20]

Another issue with health care providers, reported by Washington (2005), was the lack of cooperation for their participants, from their insurance companies, relating to the costs of medications and availability of some treatments. This is reflected in the quote below by Amy who describes her concern that she would not be eligible for laser hair removal treatment provided by the National Health Service.

Recently I have been considering getting laser hair removal treatment on the NHS but I very much doubt that my issues will fit the necessary criteria to get it on the NHS. [Amy, AU]

The findings of this research add to a growing selection of literature which through qualitative exploration of the experience of PCOS has found that women with the condition are unsatisfied with the care they receive from their health care providers. This discontent with the health care system is widespread, impacting on women in different ways and with different providers. Moreover, participants in this study expressed concern that the treatments they desired, in order to control their symptoms, would not be available to them. Overall this theme demonstrates that women with PCOS do not feel that they are supported sufficiently by the health care system and because of this, begin to educate themselves.

3.4.3.2 Education

This lack of support from health care professionals led many of the participants to self-educate. Several women commented on the ways that they had educated themselves about their condition or how to manage their symptoms of PCOS through the use of books and the internet. They accompanied these diary entries with pictures of books about PCOS or in one case, a picture of the computer and the online site they found useful in helping them educate themselves about PCOS.

In the quote below Lucy demonstrates how women with PCOS in this study sought to self-educate themselves about their condition through the use of books and the internet. She shows this by choosing to take a photograph (below) of the books she uses to not only teach herself about the condition but also to help her manage it. In the accompanying diary entry she writes:

Some books I got to try help. I learned a lot through these, especially the GI diet book – it was recommended I look into it, but it's kind of tricky to find informations that's consistent sometimes. Doctors were asked about it, and they referred me to Waterstones. Thank you, NHS. At a bit of a loss for what to do with my diet. I'm underweight, and looking both online and in book like these ... [Lucy, AU]

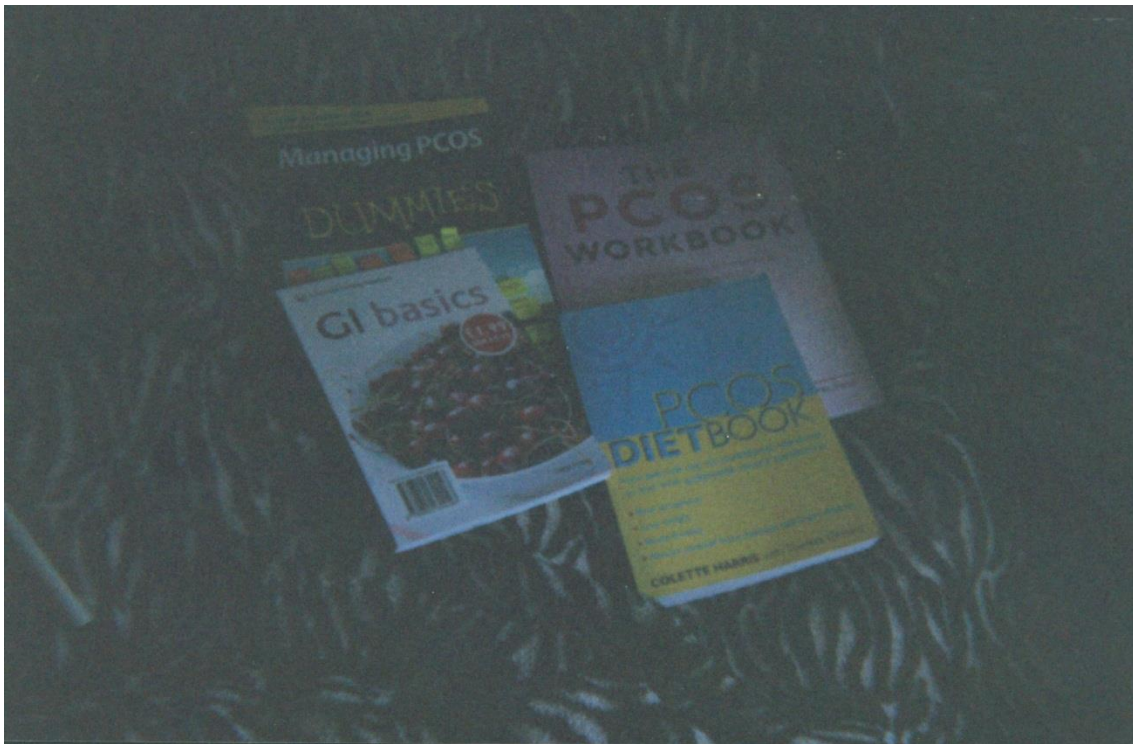


Figure 3.15 Books on PCOS, taken by Lucy.

Lucy explains that she has learnt a lot through using the books photographed. However, she writes that the information available is not consistent and that this means gaining information or an insight, therefore, is difficult. Moreover, she demonstrates how hard it is to find educational material by mentioning how even the health professionals who she approached about the condition referred her to books available through a national book store. This further demonstrates how difficult it is for women with PCOS to find information about the condition. Interestingly, the relationship between the health professionals and women with PCOS connects with another sub-theme, *The Health Care System*.

Below is another photograph taken by Jessica featuring a 'PCOS diet book'. In the accompanying diary entry Jessica describes the importance of this educational book to her.

She claims it is the 'bible for PCOS', indicating how useful and important this book has been for her and perhaps even how often she refers to it. Moreover, she explains how she has used this book to try and educate her own family about her condition as well as educating herself on PCOS.

PCOS Diet book. Do I really need to say much about this. This is the bible for PCOS sufferers. Good book with positive information I would definitely recommend it. I made my mum read this to try and get her to understand me, my moods and my eating habits a little better. [Jessica, 20]

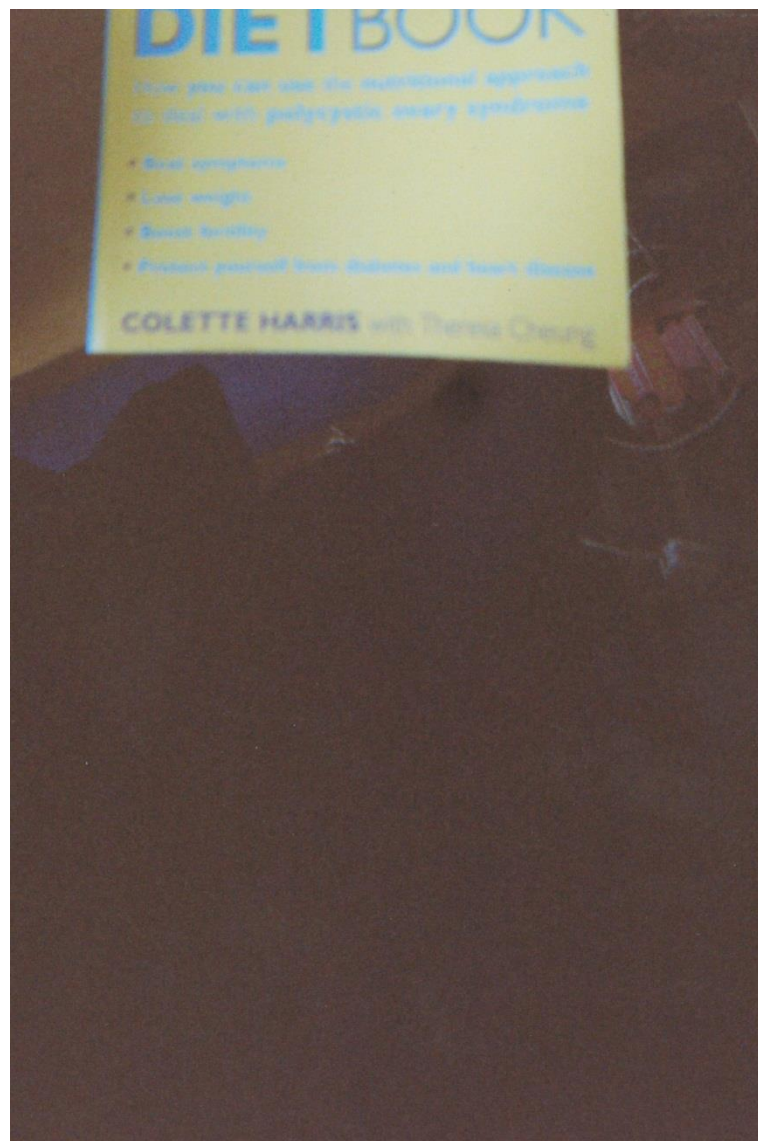


Figure 3.16 A book on PCOS, taken by Sandra.

Sandra also described how she made use of an educational diet book which she found through the recommendation of a magazine she was reading, she writes:

I came across a recommendation for this book in Red magazine and thought I should give it a go. I very specific detailed diet to naturally improve symptoms of PCOS. [Sandra, 31]

These findings mirror those of Crete and Adamshick (2011) who found that several of their participants with PCOS used online resources or printed materials in order to educate themselves about their condition; with more than one participant in their study discussing how they had used the internet to gain information. Weiss and Bulmer (2011) also reported that participants would seek information on the internet. Moreover, their participants felt that self-education helped them gain control of their symptoms. Similarly, Kitzinger and Willmott (2002) reported that participants of their qualitative study had conducted their own research into the condition as did the participants in this study.

Another way participants educated themselves, which has also not previously been reported in the published literature, was through attending 'PCOS conferences', as discussed by Jessica below. This refers to an annual conference run by the PCOS charity, Verity, where women with PCOS are given the opportunity to attend a conference featuring several talks about their condition.

I have learnt by attending PCOS conferences that eating is very important, especially eating the right things. So I try to allow 1 treat a day. [Jessica, 20]

Lucy discusses in the quote below how she gained information and educated herself about her medication through online social networking sites, in this case referring specifically to Tumblr, an internet blogging site. The use of online blogs and social networking websites has not previously been reported in the published literature for PCOS but the use of dedicated online support groups is becoming more popular for a variety of conditions, including PCOS and infertility (Holbrey & Coulson, 2013; Malik & Coulson, 2010). She also demonstrates how women with PCOS can act as educators for other women with the condition. The support offered by other women with PCOS is discussed in more detail in the main theme *Relationships*.

I've learned so much on tumblr- way more than through doctors. I'm afraid to take Metformin (though I know it's coming) because it can make you feel so sick, and it was only through tumblr that I was able to hear about alternatives. Talking to other women with it in
INVALUABLE. [Lucy, AU]

The quotes and photographs displayed demonstrate how women with PCOS seek to educate themselves through the use of books, social networking and media sites and through attending conferences in order to improve how they live with their condition, understand it and manage their symptoms: all of which aide in improving their quality of life. Similar to the women with PCOS in this study, Holman and Lorig (1992) suggest that whilst it is the health-care professional's role to facilitate an individual's self-management, in long-term conditions, the patient often becomes the most knowledgeable person concerning their condition.

3.4.3.3 Relationships

This use of websites and other media sources also helped one of the women in this study to communicate with other women with PCOS. Stephanie demonstrated this by taking a photograph (below) of her computer screen and the Verity website. Stephanie accompanied this photograph with a diary entry which describes how she feels 'less isolated' when using websites and when watching television shows which may feature other women with PCOS.

Finding out about other people's experiences through media like the verity website & channel 4's food hospital, helps me feel less isolated and to realise that there are people who suffer more than I do. I also like how the discussio boards and local groups (verity) mean I can talk to other people who actually 'get it'. Although you do get a few strange looks when you're sat in a coffee shop talking openly about menstruation and hair removal. [Stephanie, AU]

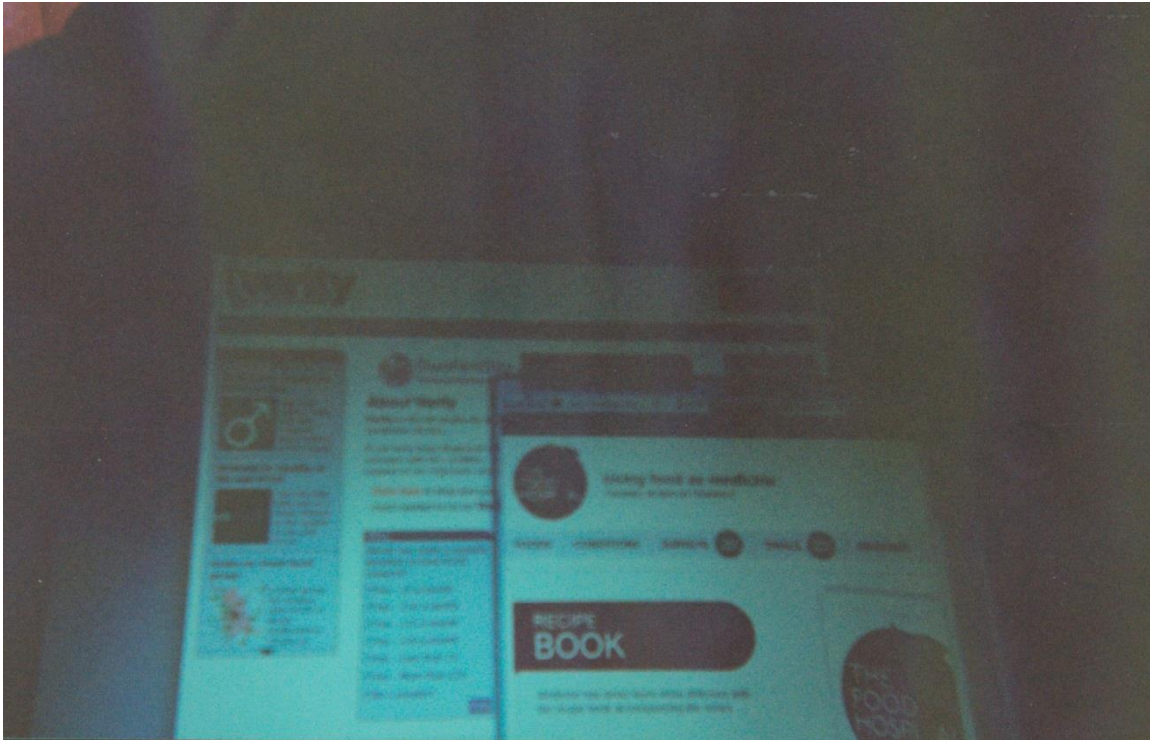


Figure 3.17 A picture of the verity website on a computer screen, taken by Stephanie.

Women with PCOS often felt that their condition impacted on their relationships with other people. The theme of relationships has not previously been explored in any depth by the published qualitative literature looking at PCOS. Previous research exploring the impact of online support for women with PCOS found that women with PCOS derive benefit from using dedicated online support groups and realising that they are not alone (Holbrey & Coulson, 2013). Additionally, Holbrey and Coulson suggest that using online support groups can also benefit in terms of accessing information and advice which may not be forthcoming from health care professionals. Similarly, Weiss and Bulmer (2011) found that women with PCOS accessed dedicated online support groups in order to gain information. Chung (2013) also argues that individuals who are dissatisfied with the support they receive offline, are more likely to prefer social interaction in online support groups. The use of the Verity website by participants in this study supports the findings of previous research (Holbrey & Coulson) and suggests that future research should explore how women with PCOS make use of dedicated online support websites for PCOS.

Some of the women in this study took photographs of their partners, and some of their pets, to demonstrate how these relationships influence their quality of life whilst living with PCOS.



Figure 3.18 A photograph of their wedding ring, taken by Sara.

In the quote below Sara describes how she perceives the impact of her PCOS on her husband. She explains that because PCOS negatively affects her in terms of her weight and self-perception, this then passes on to her husband whom she finds it difficult to accept compliments from, suggesting that having PCOS causes friction between herself and her husband even when her husband is complimentary. Sara accompanied this diary entry with a picture of her hand and wedding ring (above).

This represents my husband. My PCOS affects him because my weight affects me & how I feel about myself. It's hard to feel sexy & accept compliments from him when I'm nearly 18 st. [Sara, AU]

Denise also wrote in her diary about her husband, as shown in the quote below. However, slightly differently to Sara, Denise describes how her husband supports her. She explains how

her husband supports her through ‘patience and calmness’ and optimism about their chances of conceiving and reassuring her of his continued love despite PCOS, also reflecting the *Positive Outlook* theme.

My husband is a wonderful support to me and bears all this PCOS stuff with patience and calmness. He remains optimistic about our chances of having a child together. He always says he loves me no matter what. I am immensely grateful to him. As for the cat, he is our “furry baby” and provides comfort and cuddles! [Denise, 30]

Denise also mentions in the quote above that their cat is their ‘furry baby’, suggesting that although Denise may have trouble conceiving due to her PCOS symptoms, her pet acts as a potential surrogate child who ‘provides comfort and cuddles’. Linda also took a photograph of their pet dog (below) suggesting that having a pet may have an impact on her quality of life. The notion of pets acting as a support system for women with PCOS has not previously been reported in the published PCOS literature.



Figure 3.19 A photograph of their dog, taken by Linda.

Previous research suggests that having a pet may be beneficial to an individual's health (Antonacopoulos & Pychyl, 2010; Bonas, McNicholas & Collis, 2000; Jennings, 1997). This is supported by Allen, Blascovich and Mendes (2002), who in a study exploring the impact of pets on cardiovascular activity, found that people with pets had lower heart rates and blood pressure levels. Allen et al. (2002), therefore, propose that individuals perceive their pets as important, supportive parts of their lives.

Within long-term condition management, Brooks et al. (2012) explored the impact of pets and their role, suggesting that pets provide a specific and significant role in long-term condition management, and are not substitutes for human relationships. Pets were deemed to provide unconditional support and companionship that was not always apparent in human interactions. Ryan and Ziebland (2015) suggest that an individual's relationships with their pet can be downgraded or overlooked in qualitative research, but that pets are important agents in the health experiences of some individuals and can offer unequivocal support. Moreover, Allen (2003) suggests that individual's describe their pets as important and cherished family members, as can be seen by Denise in the quote above.

In the quote below Jessica describes a situation where someone she considered a friend was un-supportive when seeing stretch marks on her stomach which were a result of losing the excess weight many women with PCOS gain. This demonstrates how people can lack understanding of the condition and its impact and how, in turn, this can be unsupportive to women with PCOS.

My lowest point was when a boy I thought was a friend when he saw my stomach went "ew oh my god it looks like youve had a kid." No – ive been fat and lost a lot of weight. [Jessica, 20]

Radley (2004) suggests that when an individual lives with long-term illness, family and friends are likely to offer help. However, individuals with long-term illness may 'cover up' or conceal their condition from others, also known as 'passing' (Charmaz, 1997; Friedman, 2002). Consequently, they may have to decide who to disclose their condition to, and when to do this, in order to maintain these relationships. Similarly, Charmaz (1997) suggests that people with long-term illness consider what they should tell other people, and what they need

to tell other people. Indeed, Radley advises that ‘the price of the healthy person’s compassion is the concealment of things by the afflicted, things that could be considered abhorrent’ (p.158). Moreover, de Ridder (2004) suggests that friends may have problems when responding to the altered condition of someone with a long-term illness. This reflects the experience of Jessica, detailed above, whose friend was unkind to her upon disclosure of her stretch marks.

The quotes and photographs displayed demonstrate how women with PCOS can feel about their relationships and the impact of these on their quality of life, or alternatively, how their PCOS may impact their relationships. Many aspects of this theme have not previously been reported in the published literature and need to be further explored in order to gain a better understanding of how women with PCOS experience their relationships.

3.5 Discussion

This research explored the impact of PCOS on quality of life from the participant’s perspective and produced three super ordinate themes: Control, (sub-themes Symptom Management and PCOS as Controlling) Perception, (sub-themes Feminine Identity and Positive Outlook) and Support, (sub-themes The Health Care System, Education and Relationships). These findings shed new light on the perceived positive aspects of living with PCOS and the supporting role that pets; online support groups and social networking websites play for women with PCOS.

The findings in this study mirror those of previous research in long-term conditions, in that an individual’s ability to control their condition can influence how they experience it (De Ridder, 2004). The theme of *Control* particularly reflected previous research which suggests that self-management routines are important for individuals to feel in control of their condition (De Ridder; Leventhal et al., 2003). In addition, Barlow et al. (2002) suggest that an individual’s ability to monitor their condition is necessary to maintain a satisfactory quality of life. Moreover, Barlow et al. (2002) suggest that self-management approaches are made up of several components including: information, drug and symptom management, management of psychological consequences of the long-term condition, life style, social support and communication; although these categories are not mutually exclusive. Each one of these aspects of self-management was evident in this study from gaining information to support and communication.

Barlow et al. (2002) suggest that due to the self-management aspects of a condition, responsibility for the management of a long-term condition will gradually change from that of the health professional, to the individual. Furthermore, Clark et al. (1991) suggest that for an individual to successfully manage their condition, they must have sufficient knowledge of the condition and how to manage it. Moreover, Friedman (2002) suggests that when an individual with a long-term condition seeks information around their condition, this can be an adaptive coping method. However, should the individual insist on information which health care professionals cannot provide they can become dissatisfied with the process of information seeking, the coping technique then becomes maladaptive. This was reflected in the findings of this study through the theme *Support* and particularly the sub-themes of *The Health Care Professionals* and *Education*, whereby participants in this study sought to educate themselves on their condition in order to manage and control it, often due to dissatisfaction with the information provided by their health care professional.

As mentioned, this research highlighted the lack of support the participants received from health care professionals, as discussed in previous PCOS literature, (Castillo, 2008; Crete & Adamshick, 2011; Holbrey & Coulson, 2013; Kitzinger & Willmott, 2002; Snyder, 2006; Washington, 2005). This lack of support often led the participants to educate themselves using books and the internet. Whilst this research is the first study within the PCOS literature to report that women with PCOS use online blogging websites such as Tumblr to gain information and form relationships with other women, the act of searching for information and gaining support from others is not new. Certainly, Friedman (2002) suggests that a request for reassurance from others is a type of coping technique which can be adaptive, as talking to others can be supportive, but also maladaptive should the requests for reassurance become excessive. Leventhal et al. (2003), has similarly reported that individuals with long-term conditions make use of treatment suggestions made by friends or acquaintances over the internet. Similarly, Holbrey and Coulson (2013) found women with PCOS use dedicated PCOS online support groups to access information and advice, and connect with other women with PCOS. However, Moorhead et al. (2013) suggest that whilst social media, such as Facebook and blogging websites, bring a 'new dimension' to health care, health information exchanged on social media ought to be monitored for quality and reliability of the health care information being disseminated. The use of social media by participants in this study could therefore be problematic for individuals who may receive wrong or

inadequate information either from blogging websites such as Tumblr (used by one participant in this study) or from other people on social networking sites (such as Facebook).

Due to the risk of patients engaging with inaccurate information on the internet, McMullan (2006) suggests that health care professionals should guide patients to reliable and accurate health websites and repositories of health information. This provision of information from the health care professional to the patient is known as the 'internet prescription' (Gerber & Eiser, 2001). It would be sensible, therefore, to suggest that health care practices and professionals introduce websites which would allow their patients to access correct information about their PCOS and enable them to access an area in which they could discuss their condition with other patients. Moreover, input from a health care professional to this environment would enable women with PCOS to feel supported by their health care professional; something which the participants in this study felt was inadequate.

This study also found that women with PCOS who experienced the symptoms of hirsutism and fertility issues felt like they were not meeting traditional feminine ideals. In the wider literature, Hirsch and Hirsch (1989) found that women who experienced infertility perceived themselves as more masculine than controls and experienced greater discontent and emotional investment over time than their partners. Furthermore, they found that some women who experienced infertility may have felt unfeminine and incomplete, as was reported by participants in this study and previous PCOS research (Kitzinger & Willmott, 2002). Callan and Hennessey (1989) explored perceptions of women with infertility issues (both explained and unexplained) in comparison to women who were mothers and those who were voluntarily childless. They suggest that those women who experience infertility may present with a heightened sense of femininity, by which they embody the traditional roles associated with being a mother, demonstrating an increased perception of motherhood and its relation to being feminine. As a result, Callan and Hennessey suggested that women who are experiencing infertility ought to be counselled about their perceptions of a childless lifestyle. Similarly, women with PCOS who are experiencing symptoms of infertility and feel that their feminine identity is threatened, could receive support from health care professionals with regards to their identity without children.

This study also highlighted how women with PCOS retained a positive outlook despite living with their condition and its symptoms. It demonstrated how women remained hopeful and

optimistic about their future living with PCOS in the face of uncertainty; particularly with regards to future fertility. Research has previously suggested that optimism is a significant predictor of positive health outcomes (Rasmussen, Scheier & Greenhouse, 2009). Indeed, Litt et al. (1992) found that for women undergoing IVF, a fertility procedure often undertaken by women with PCOS, the participants who were most optimistic were the least distressed after unsuccessful fertilisation. Bleil et al. (2012) similarly report that being pessimistic may be a risk factor for IVF treatment failure. This suggests that being optimistic may be advantageous for women with PCOS who are suffering with infertility and implies interventions which promote hope and optimism may be beneficial. However, the longer term benefits of optimism are less clear (Cohen et al., 1999; Segerstrom & Sephton, 2010) and so the long-term effects of having a positive outlook with no improvement need to be examined.

The number and length of diary entries made by participants varied from one A4 page to 17 A4 pages (single-side, wide margins). This variety in diary entries is discussed by Braun and Clarke (2013), who suggest that this is to be expected when asking participants to keep diaries as some participants may provide 'rich narratives' and others may provide 'little affective commentary' (p.151). Elliot (1997) suggests that participants may become more confident when making diary entries over time. As such, future research employing a researcher-solicited diary should consider extending the data collection period to allow participants to become more comfortable with the process of making diary entries.

The use of diaries in this research also allowed the researcher to collect data whilst being minimally intrusive (Alaszewski, 2006). Moreover, Alaszewski proposes that diaries allow the participants to record what they consider important and relevant, including events, activities, interactions and feelings. Bolger, Davis and Rafaeli (2003) similarly suggest that diaries allow participants to record their daily lives in a natural context, enabling the researcher to explore the participants experience in a way that traditional methods do not allow. Using diaries, therefore, enabled an investigation into how women with PCOS in the UK perceived and defined their quality of life, with minimal researcher interference.

Several participants created entries in their dairies which referred specifically to photographs they had taken; however, upon development of the camera there were no associated photographs. It can be assumed that the photographs either were not taken properly or failed to develop. This issue, however, does demonstrate the advantage of asking participants to

complete diary entries for photographs rather than asking them about photographs at a later date which have been developed, as in previous research (Frith & Harcourt, 2005). Moreover, Thompson et al. (2008) state that by carrying out photovoice research at two different time points (time of photograph and time of interview about photograph), many participants had forgotten why they had taken the photo. In this way researcher-solicited diaries allow the researcher to see the photographs in an accurate context reducing retrospection and recall bias (Alaszewski, 2006; Bolger et al., 2003).

There were limitations with this study; primarily, the attrition rate for this research was high. A large sample of participants were recruited and sent study packs (N=34) and only nine participants returned their packs, despite reminder emails. A number of participants also stated that they had returned completed packs but these never arrived. Although there were a small number of participants, this replicates other photovoice research which had similar sample sizes (Duffy, 2010; Thompson et al., 2008; Vaughn et al., 2008; Wiersma, 2011) and may therefore be related to a methodology which places quite a high burden on the participant.

The high attrition rate could also be due to a lack of a personal relationship between the participant and researcher, as participants were only in contact with the researcher via email. Booth and Booth (2003) suggest that many women in their photovoice study found it difficult to use the camera film so put the camera aside and then forgot to go back to it. It is possible, therefore, that the women in this study simply forgot to use the camera. Baker and Wang (2006) similarly reported issues of high attrition in their photovoice research; they, however, suggest that this may be due to the number of steps participants have to take in order to complete the research. Indeed, some participants in this research may have completed the study but failed to return the study pack. Consequently, the lack of responses may have limited the findings of this study and potentially biased the findings to represent those women who engaged with the research who may be more able to cope with their PCOS or, indeed, those who feel less supported.

A further restriction on the participant sample was that participants were all recruited via a post on the website of PCOS charity, Verity and were self-selecting. Therefore, it is suggested that all the women in this research were actively seeking support for their condition and were engaged with a larger PCOS community. Moreover, there is a possibility that the

participants were not clinically diagnosed with PCOS, even though they engaged with these communities as participants in this study self-reported their PCOS status. However, the included participants presented with a variety of symptoms, including symptoms of: weight, acne, hirsutism, infertility and symptoms surrounding blood sugar and hormone control. This suggests that they represented the symptom profiles of the four phenotypes of PCOS as detailed by the 2003 Rotterdam criteria (2004).

Participants were also informed that they would need to gain verbal informed consent from any person they wished to photograph (or the appropriate guardian) which presents another limitation for this research. Participants were informed that any pictures they did take of people would not be published and their photos would only be used for the purpose of analysis. Frith and Harcourt (2005) employed similar ethical guidelines in their photovoice study and claimed that this may have influenced or restricted what participants felt able to take photographs of. Moreover, they state that the exclusion of using images with people in may have resulted in useful data being lost.

To overcome this potential limitation, future photovoice research could require the participant to gain written informed consent from the individual being photographed (Wang & Redwood-Jones, 2001). Alternatively, participants could use 'consent vouchers' (small consent forms) to gain consent from individuals they wished to photograph (Hannes & Parylo, 2014). However, Hannes and Parylo (2014) found that participants in photovoice research often avoided approaching individuals for consent, this was due to either a reluctance to approach people or because participants perceived the extra step of gaining written consent as an annoyance and unpractical. Consequently, Hannes and Parylo suggest that to reduce avoidance of gaining consent; participants should receive practical training on how to approach individuals to gain informed consent, thus making the participant more comfortable when approaching people for consent. Alternatively, the photographer may demonstrate on their consent form that they had received consent from the individual being photographed, this could be done through the return of the informed consent form to the researcher. However, there is still a potential risk that the participant may not gain approval from the individual they wish to photograph. Certainly, Crow and Wiles (2008) suggest that to ensure anonymity, as far as possible, visual material should be excluded from research projects, or projects should only include visual material that does not feature an individual. Moreover, they claim that whilst an individual may give consent for their images to be used,

they may later be dissatisfied with how their image is portrayed once reported (Crow & Wiles). As such, researchers should avoid the use of photographs of individuals in publications without personally receiving their explicit informed consent.

Wang (1999) suggests that the choice of camera in photovoice research should be guided by the researcher and any practical considerations. Disposable cameras were chosen as their use would ensure that all participants' images were of the same quality and size and the provision of disposable cameras meant that all individuals (who met the inclusion criteria) would be able to participate in the research should they wish to, as participation was not dependent on access to a camera. Similarly, the majority of previous photovoice research in health has utilised disposable cameras (Aubeeluck & Buchanan, 2006; Baker & Wang, 2006; Moffitt & Vollman, 2004; Thompson et al., 2008; Valentine & Knibb, 2011; Wang & Pies, 2004; Wiersma, 2011). Whilst providing participants with disposable cameras ensures that all potential participants could take part in the research, the use of disposable cameras may have limited this research as participants may have been unwilling to return cameras if they regretted taking a specific photograph, and there were also technical issues with the camera itself, such as photographs not printing or being unclear.

Future qualitative research employing photovoice methodology would be useful to further explore the impact of PCOS on quality of life from the participant's perspective, and how they live with PCOS on a day-to-day basis. However, there are several ways that this study could be improved upon and added to; primarily through the use of smart phones for photograph taking. Research into the use of camera phones suggests that individuals have camera phones always on hand (Kindberg, Spasojevic, Fleck & Sellen, 2005). Indeed, Boulous, Wheeler, Tavares and Jones (2011) suggest that smartphone technology may be able to achieve lower attrition rates in health research due to its ease of use. One way of achieving this may be through a smartphone application such as the 'PhotoVoice™' application which allows you take a photograph and then record and attach a sound file to that photograph before sending it via email or to social media sites (Kiger, 2016). However, there is yet to be research which explores the efficacy of using smartphones for photovoice research.

As participants in this study demonstrated a familiarity with social networking websites, integrating social media with the taking of photographs could lead not only to lower attrition

but an interesting new way of generating data for analysis. Many mobile phones now have the capability to not only take photographs but to share them instantly to a variety of social networking websites such as Facebook (Wilhelm, Takhteyev, Sarvas, Van House & Davis, 2004). Indeed, 874 million monthly active users used Facebook mobile products as of September 30th 2013 (Facebook, 2014). This suggests that participants would be familiar with the actions of taking photographs and uploading them to a social networking website which could then be accessed by the researcher and participants: allowing for instant data creation and group discussion of the images. This discussion of the photographs could act as an online interview or focus group as has been demonstrated in previous offline photovoice research (Booth & Booth, 2003; Duffy, 2010; Thompson et al., 2008; Wiersma, 2011). In line with this, Strack et al. (2015) recently developed a web-based tool, which will lead individuals through the steps and ethics of photovoice, to enhance ‘the reach and impact of photovoice’ (p.192). The tool would enable participants to be trained in photovoice and give them a dedicated web space to share their photos. As such, this tool could be used by researchers who wish to use photovoice in their research. However, to the researcher’s knowledge, there is no published photovoice research which utilises an approach using smartphones or an online data collection tool.

This study aimed to gain an understanding of how women with PCOS perceived quality of life. As such, participants in this study were not given a definition of quality of life before taking part. Whilst this may be seen as a limitation to the study, this enabled participants to conceptualise what quality of life meant to them. This, therefore, allowed for the research to explore the perceptions of quality of life for women with PCOS, rather than the data being created according to the researcher’s questions or according to a specified definition that may not have fully captured the quality of life of women with PCOS. As such, the data in this study represents how participants perceive their quality of life, and the impact PCOS may have on it. It is of note, however, that the findings from this study reflect many of the domains of quality of life previously reported, such as; physical health, psychological health, independence, social relationships, occupational activities, and personal beliefs (Fallowfield, 1990; WHOQOL Group, 1994). As such, aspects of PCOS identified by the participants mirrored the psychological, physical, social, and environmental and level of independence factors that are thought to make up the quality of life construct (Fallowfield, 1990; Testa & Simonson, 1996; WHOQOL Group, 1994).

This study revealed how women with PCOS in the UK perceive and define their quality of life. The women in this study also captured the impact of PCOS on their quality of life, according to their perceptions, this included: relationships, their sense of femininity, the physical impact of symptoms, their social activities and the management of their condition. These findings reflect the domains of quality of life highlighted by the WHOQOL group (1994) including: physical and psychological health, their level of independence, their social relationships and their environment. Moreover, aspects of the theme *Positive Outlook* reflected the spiritual/religion/personal beliefs domain reported by the WHOQOL group. By capturing their daily experience, this study helped to further understanding of the impact of PCOS on quality of life of women in the UK, on a day-to-day basis from their perspective. Dissemination of these findings to health professionals may reduce the lack of understanding of the daily impact of the condition on quality of life, therefore enabling them to not only provide a better health care service to women with PCOS but also allowing women with PCOS to feel more supported.

Chapter Four - 'Everything's from the inside out with PCOS': Exploring women's experiences of living with Polycystic Ovary Syndrome (PCOS) and co-morbidities through Skype™ interviews.

The previous chapter highlighted how women with PCOS engage in self-management behaviours in order to control and cope with their condition (De Ridder, 2004). This includes hair removal methods, taking medications (both prescribed and supplemental), engaging with diet and exercise, and using a variety of skincare routines. Moreover, it demonstrated that women with PCOS engage in self-education in order to better manage their condition, often resulting from a perceived lack of information and support from health care providers (Holroyd & Creer, 1986). The findings also highlighted how women with PCOS sought support from relationships, particularly those with other women with PCOS and their family. The findings from Chapter Three also demonstrated that the participants often felt unfeminine due to their condition and as such, their PCOS had a negative impact on their identity as a woman. Moreover, Chapter Three revealed how women with PCOS perceive and define their quality of life. It also furthered understanding of the impact of PCOS on quality of life for women with PCOS in the UK, from their perspective.

4.1 Introduction

Participants in Chapter Three were, however, excluded if they had any other condition besides PCOS, in an attempt to provide a greater understanding of the impact of PCOS on quality of life, specifically. However, women with PCOS are likely to experience co-morbid conditions including cardiovascular disease, diabetes, endometrial cancer, depression and anxiety (Benson et al., 2009; Chittenden et al., 2009; Deeks et al., 2011; Marks et al., 2005; Navaratnarajah et al., 2008). In addition, during recruitment for the photovoice study, many potential participants that contacted the researcher wishing to take part were excluded from the study as they experienced, or were diagnosed with, another condition (or conditions) in addition to their PCOS. Thus, it is necessary to explore, and gain an understanding of how women with PCOS in the UK live with and perceive their condition, and any presenting co-morbidities on a day-to-day basis. As such, this chapter reports the findings from additional qualitative research that aims to explore further how women with PCOS perceive and understand their condition on a daily basis, but it does not exclude women with PCOS who present with other conditions be they acute or long-term.

Many women with PCOS are likely to develop, or experience more than one long-term physical and/or mental health condition, including type 2 diabetes, cardiovascular disease (Ong, Theodoru & Ledger, 2006; Thomson et al., 2010), irritable bowel syndrome (Mathur, Ko, Hwang, Low, Azziz & Pimentel, 2010), thyroid disorders (Janssen, Mehlmauer, Hahn, Öffner & Gärtner, 2004; Kachuei, Jafari, Kachuei & Keshteli, 2012; Sinha et al., 2013) and eating disorders (Jahanfar, Eden & Nguyent, 1995; McCluskey, Evans, Lacey, Pearce & Jacobs, 1991). Studies also suggest that there is a higher prevalence of PCOS in women with bipolar disorder (Ragson et al., 2005; Jiang, Kenna & Ragson, 2009). Women with PCOS are also more at risk of developing depression (Bhattacharya & Jha, 2010) and anxiety (Laggari et al., 2009) disorders. Coffey and Mason (2003) similarly report that women with PCOS have higher levels of depression and psychological morbidity than controls. Indeed Cipkala-Gaffin, Talbott, Song, Bromberger and Wilson (2012) found that women with PCOS have a higher prevalence (31%) of mild or moderate depressive symptom levels compared to a control group (17%). Deeks et al. (2011) also report that women with PCOS have increased anxiety, depression and negative body image compared to women without PCOS. Likewise, Ching, Burke and Stuckey (2007) argue that women with PCOS have an impaired quality of life and an increased prevalence of psychological morbidity. Of concern, Elsenbruch et al. (2006) report that psychiatric illnesses in women with PCOS may go undetected: 22 of 143 women diagnosed with PCOS but who were un-medicated (three or more months) had a possible un-diagnosed psychiatric disorder according to the Symptom Check List 90 (SCL-90-R; Derogatis, 1977). It is clear therefore that women with PCOS can also experience co-morbid conditions that may have a negative impact on their quality of life. However, the majority of research investigating PCOS and co-morbid conditions has been quantitative or clinical in nature. As such, there remains a need for research that not only furthers understanding of the impact of PCOS, but also sheds light on the experiences of those women who also live with a co-morbid condition.

To date, there are no papers which explore how women with PCOS live with, and manage their condition, and any co-morbid conditions they also experience. Certainly, Moreira and Azevedo (2006) argue that incorporating qualitative approaches into PCOS studies could contribute to our understanding of the psychological impact of the disease. However, only a handful of studies have explored PCOS from a qualitative perspective (for example, Crete &

Adamshick, 2011; Holbrey & Coulson, 2013; Kitzinger & Willmott, 2002; Percey et al., 2009; Synder, 2006; Washington, 2008). Moreover, of those studies, all have (or do not specify) an exclusion criteria resulting in women with PCOS, who experience co-morbidities, being excluded from these studies. Further exploration of this experience would therefore aide our understanding of the psychological impact of PCOS, and other conditions, on daily life. This study, therefore, aims to explore and gain a further understanding of how women with PCOS in the UK live with and perceive their condition, and any presenting co-morbid conditions, on a day-to-day basis. It is the first such study to explicitly explore the experiences of women with PCOS who experience co-morbid conditions; this is of particular importance given the high proportion of co-morbidities discussed earlier in this chapter.

4.2 Online Research Methods

As discussed in Chapter Two, there is a need for qualitative research to further understanding of the impact of PCOS on the day-to-day lives of those women who experience the condition, and any co-morbid conditions. However, women with PCOS have also been shown to be socially isolated (Kitzinger & Willmott, 2002), this was also demonstrated by participants in Chapter Three; therefore, a method of data collection that accounts for this is needed. Seymour (2001) suggests that the use of online data collection methods enable the researcher to access inaccessible domains, such as hard to reach populations or socially isolated groups. Kraut et al. (2004) also argue that online research could make apparent psychological phenomena that do not exist in traditional settings. Moreover, Sullivan (2012) proposes that there is potential for data collection in social research through the use of technology such as Skype™ and Google Hangout. As such, online research may enable access to a socially isolated population such as women with PCOS (as discussed in Chapter Two).

Deakin and Wakefield (2013) suggest that online synchronous interviews, such as those conducted on Skype™, are a useful replacement of traditional face-to-face interviews for qualitative data collection. They describe several advantages of using Skype™ to conduct interviews including allowing more flexibility for the researcher and participant, and being more cost and time efficient. Janghorban, Roudsari and Taghipour (2014) also argue that Skype™ offers a useful alternative to face-to-face interviews and is suitable for conducting individual interviews. Previous research using Skype™ has explored online health forums (Fan, Lederman, Smith & Chang, 2013) and online psychiatric consultations (Williams et al., 2014). Williams et al. (2014) found that in their study there was a high acceptability of online

consultations via Skype™ amongst their participants. This suggests that Skype™ is a viable way to conduct online research. Accordingly, this study explored how women with PCOS live with and perceive their condition, and any co-morbid condition(s), on a day-to-day basis through online Skype™ interviews.

4.3 Methods

4.3.1 Participants

Participants were recruited via the social networking website, Facebook. A recruitment post (Appendix F) was posted to different PCOS support groups available on Facebook. The inclusion criteria for this study were women: aged 18 and over, who lived in the UK and experienced symptoms of PCOS. Ten participants agreed to participate in the study and were interviewed for between 40 and 90 minutes. Of these participants, nine presented with symptoms indicative of psychological or physical co-morbid conditions, and as such, only nine participants were included in the analysis.

Participants' ages ranged between 20 to 41 years old (mean age = 31.71 years); two participants chose not to disclose their age. Length of diagnosis ranged from one year to 14 years (mean length of diagnosis = eight years). Four participants reported a clinical diagnosis of depression, one participant reported a clinical diagnosis of anxiety. Other co-morbid conditions experienced by participants included: irritable bowel syndrome, asthma, eczema, Ehlers Danlos syndrome, hypothyroidism, migraines and Fibromyalgia.

4.3.2 Materials

All potential participants received an information sheet (Appendix G) and a consent form (Appendix H). Interviews were conducted using Skype™. Participants were given the option to use voice call only or video call; all participants decided to take part via voice call only. Skype™ is an online method of making free video or telephone calls; it also allows for individuals to send text based messages to one another for free. The interviews were recorded using Evaer computer software downloaded from the company's website (Evaer Technology, <http://www.evaer.com/index.htm>).

4.3.3 Procedure

After participants had registered their initial interest in taking part in the study via email to the main researcher, they were sent an information sheet and a consent form by return email.

They were informed that they did not need to fill anything in but were advised to read both documents before deciding if they wished to take part in the research, thus ensuring participants had sufficient time to consider the implications of taking part in the research (NHS HRA, n.d). Participants were able to choose whether to take part in a focus group, or an online or face-to-face interview. All participants opted to take part in an online interview. Consequently the participants emailed to say they would like to take part arranged an interview appointment with the researcher and informed the researcher of their Skype username.

At the time of the scheduled interview participants were called through Skype™ (Microsoft, UK). The researcher then reminded the participant that the Skype™ call was being recorded. Participants were then asked to create a unique identifying code made up of three letters or numbers that they would remember and informed that should they wish to withdraw from the research then all they need do is contact the researcher with this code (BPS, 2013). After participants had created a unique identifying code they were then given the opportunity to ask any questions they had. A copy of the statement of informed consent was then sent to the participant using the text based message service within Skype™. At this point participants were asked to type whether they agreed or disagree to taking part in the research. Finally participants were reminded of their right to withdraw from the research up to three weeks after participation, and also of their right to stop the interview at any time. Interview questions included ‘could you describe a typical day living with PCOS?’, ‘Have you changed the way you deal with your PCOS and its symptoms over time?’ and also ‘If you experience any other type of illness or disorder, how do you manage this?’(Appendix I). After completion of the interview, participants were emailed a study debrief (Appendix J) and given the opportunity to ask questions.

4.3.4 Ethics

Research complied with The British Psychological Society’s ethical guidelines (BPS, 2009) and their guidelines for internet-mediated research (BPS, 2013) and ethical approval was obtained from the Psychology Research Ethics Committee at the University of Derby (Ethics Approval Number: 06012-SW).

4.3.5 Analysis

The online interviews were transcribed and then analysed using an inductive thematic analysis (Braun & Clarke, 2006). Thematic analysis is a method for identifying and reporting themes within the data, which organises and describes the data in detail (Braun & Clarke). To analyse the data according to the six steps recommended by Braun and Clarke, the transcript was first read and re-read and then initial codes were generated. Next the initial codes were sorted into potential themes. The themes were then reviewed, defined and named. Finally, the thematic analysis was written up. The final themes were reviewed by two other health psychology researchers to ensure all were in agreement and that the themes accurately represented the data (Braun & Clarke).

4.4 Findings

Participants in this study experienced a variety of symptoms including hirsutism, obesity, acne and infertility. All participants experienced other conditions, in addition to PCOS. These were both physical and psychological, three participants experienced both physical and psychology co-morbidities in addition to their PCOS. Four major themes were identified in the data: Change (Change to Life Plans and Changing Nature of the Condition), Co-Morbidities (Living with Other Conditions and Depression and Self-harm), Support (Health Care Professionals, Self-support and Relationships) and Self (Feminine Identity and Us and Them). All identifying details have been removed from the quotes and participants have been referred to by pseudonyms throughout the analysis in order to ensure that they are not personally identifiable (BPS, 2010).

4.4.1 CHANGE

The theme *Change* permeated the interviews and was discussed by many of the participants, in the two sub-themes *Change to Life Plans* and *Changing Nature of the Condition*.

4.4.1.1 Change to Life Plans

Several participants described how PCOS had caused them to change their life plans, particularly their plans to start a family. In the quote below Dawn discusses how having a large family was the ‘planned thing to do’ and what they (her and her husband) ‘had planned to do’ before they got married.

I think it did, yeah, I mean I think it might, when me and my husband first got together it was you know, my husband's one of six, I'm one of five, it was the planned thing to do and that's what we had planned to do before we got married erm but it, it, did bother me for a long time, a very long time actually, erm but I think the older I've gotten and the older we've gotten the more, I think since I turned 30, it's become less of an issue, if you like because we've just, we've got used to it. You know, when I turned 30 we'd been dealing with it for nearly ten years. So I don't know if it's erm, it might have impacted to start off with, but it's not, I don't, I used to look at children and think yeah I'd love one. [Dawn, 36]

Dawn reflects that over the last ten years, as she has gotten older, she has become 'used' to the impact PCOS has had on her and her husband's ability to have children and the family they planned. Similarly, Julie (below) states that she had been 'dreaming' about having a family for almost '30 years'. She discusses, in the quote below, how the impact of PCOS on her fertility was 'very hard to grasp' as it was something she had 'always wanted' from a young age. The quote illustrates how women with PCOS who plan or want a family may have to change the plans they had for their life and adapt to living with PCOS.

I really found it very hard to grasp that the one thing that I'd always wanted right from, well from being a little girl and playing with, playing with dollies and that sort of thing. I always knew I wanted children, even before I wanted a boyfriend. I knew that malarkey and always knew that I wanted a family and so this thing that I've been sort of looking forward to and dreaming about for nearly the whole of my 30 years was kind of like the, the rug pulled out from under my feet kind of thing a little bit and it was erm pretty horrible really. [Julie, 36]

Plans to have children, and how PCOS impacts on these, were also discussed by Kay, in the quote below; she described how she was unsure about her future fertility and the fertility treatments she was about to start.

I'm about to have a blood test done so all that's going to be a huge impact erm in my life and it's quite scary really. Well, hopefully it's going to help but it's quite scary to think that I'm going to have to go through that...and as I say by now in an ideal world I would have had a big family. I would have had lots of children erm and we don't know if we're going to even be able to have one...it's more the erm you must do it kind of now because you're running out of time as opposed to let's do it to see [Kay, AU]

Marie similarly discussed the impact of PCOS on her plans for a family and how they have changed from being a child. She describes how since she was diagnosed (at 14 years old) she has tried to become used to the idea that she may not have children.

I've sort of become used to the idea of possibly not having children 'cause when I was younger I always thought I wanna get married and I wanna have kids but now I try to think a lot more about erm the likelihood of not having children that it's not gonna be a huge plan whether or not to have children as it might not happen [Marie, 20]

Sharon also discussed the impact of PCOS alongside having a bicornuate uterus, an abnormality in the uterus, on her plans to have children.

I was having surgery to have that removed [bicornuate uterus] to try and make it viable for me to carry pregnancies and erm when I came round from the operation he said it wasn't possible...he said that he was going to tell me he thought it very unlikely that I would have a family and that the combination of polycystic ovaries and that abnormality probably made it unlikely erm that I would ever be able to carry a child full term. Erm so obviously that was quite upsetting...but I always thought I'll end up adopting or something like that erm, as it happens, he was very wrong...I did manage to have children [Sharon, 41]

Holly also discusses how she feels pressure to have children; she describes how she feels that doctors had pressured her to have children 'sooner rather than later' and the consequential impact of this on her plans of having a career before having children.

Erm I think erm every doctors tells me that I need to start thinking about having children sooner rather than later, that's quite a change erm 'cause I'm an army wife so I travel around a lot which makes it hard to get jobs and kind of puts your career on the back foot so I was hoping to establish a career, a, a settled base and then have children but I'm not sure how that's going to work out for me now. So yeah, I think I probably will have to change my plan slightly. [Holly, 25]

Holly, at a later point in the interview, again discusses how she feels a 'constant pressure' to have children as shown in the quote below.

Erm well like we touched on about the lack of control and the fear of not, of maybe not having children and you don't really know until you start trying and that, that's how I feel at the moment. That I'm, 'cause I'm not trying I don't know whether I can or can't have children. I don't know how hard it's going to be and it's erm, it's that horrible feeling well you better get on with it then 'cause you know it could take years to try and get pregnant. There's that constant pressure, it's horrible. [Holly, 25]

The impact of PCOS on the ability to conceive for women with PCOS has been highlighted previously by Snyder (2006) who demonstrated that women with PCOS felt uncertain about their ability to become pregnant. Similarly all the participants (n=10) in Washington's (2008) study expressed concerns surrounding their ability to get pregnant, and also the impact of their PCOS on conception. More recently, Sanchez and Jones (2016) explored how digital (online) teen and women's magazines portrayed women with PCOS. They found that PCOS was depicted as a barrier to childbearing and starting a family and subsequently, this impacted on the role of women with PCOS as wives and mothers (this is discussed further in the sub-theme *Feminine Identity*). Having a child is considered an important life goal for many people (Thomson, 2011). This study, however, is the first to discuss the pressure women with PCOS feel to have children earlier in life than they may have originally planned due to pressure from health care professionals.

The impact of infertility on life plans, whilst not previously being reported in the PCOS literature, is similar to experiences of women in other conditions or undergoing treatments that can impact on women's fertility, such as being diagnosed with the BRCA1 gene and the impact of cancer treatments on fertility. Some treatments for cancer such as chemotherapy and radiotherapy can also have an impact on a woman's fertility causing them to become infertile (Dow, 1995; King et al., 2012; Lamb, 1995; Maltaris et al., 2007; Sonmezer & Oktay, 2006). Maltaris et al. suggest that female cancer patients are not adequately advised about the impact of treatment on their fertility and suggest that women experiencing this need support from psychological specialists due to the additional psychological stress, loss of control, grief and depression associated with infertility (Carter et al., 2005). However, differently to those women with PCOS progress is being made in fertility preservation during cancer treatment in order to give women who have undergone aggressive treatments, a chance to conceive (Dow, 1995; King et al.; Maltaris et al.).

Salmela-Aro and Sikkari (2008) suggest that the experience of infertility is an ‘unwelcome interruption’ to those individuals who expect to become parents. Loss of control over future plans and life goals has also previously been reported as a reaction to infertility (Dunkel-Schetter & Lobel, 1991). In a review of literature exploring the impact of infertility, Dunkel-Schetter and Lobel (1991) found that 40% of the studies reported that participants felt that they had lost control over their future. Charmaz (1997) suggests that time helps an individual to situate themselves and define their self-concept. She argues that it is therefore necessary for people with long-term conditions to restructure time and how they perceive their future. Moreover, Charmaz states that for individuals with long-term conditions, they may have to ‘abandon their previous hopes and plans’ (p.21), thus reflecting the experiences of the participants in this study. Similarly, Moos and Tsu (1977) suggest that when an individual experiences a loss of a function due to a long-term illness, in this case fertility in women with PCOS, they need to acknowledge and mourn this loss and then prepare to live with the loss of function going forward.

4.4.1.2 Changing Nature of the Condition

Several participants describe the changing nature of their PCOS symptoms and their inability to predict how their condition will change over their lifetime. For example, Julie describes how after making the decision to stop trying for a second child she returned to taking the oral contraceptive pill, however, it did not work in the same way.

I went back on the pill ‘cause I thought...let’s put it back to bed [trying for a child] ..., I thought going on the pill would help because I thought it would mask it and control it again. Only this time round it made absolutely no difference erm other than it got me back into a regular cycle...it made no difference whatsoever. [Julie, 36]

The quote above demonstrates how it can be difficult for women with PCOS to predict how their condition, and treating it, will change over time. Crete and Adamshick (2011) have similarly reported that women with PCOS were frustrated due to dealing with the uncertainties of symptoms and diagnosis. In addition, Castillo (2008) stated that women with PCOS felt like they did not have much control over their syndrome and its symptoms.

Similarly, Dawn states in the quote below that her PCOS symptoms have ‘got worse over the years’ demonstrating how the symptoms of PCOS are unstable.

It's definitely just got worse over the years. A lot worse erm I think, I think from the age of 25 its suddenly started kicking off erm with you know having to start taking care of you know, the hair issue and it just, as I said, it just seems to be getting worse. [Dawn, 36]

Participants in Snyder's (2006) study similarly described how their body was ‘changing’ (p.388) as a result of PCOS and that dealing with the ‘uncertainty of the syndrome’ (p.390) was frustrating. Similarly, Holly discusses the changing nature of her moods as a result of PCOS in the quote below. She describes how she feels she has ‘no control...whatsoever’ and how she has taken medication to try and control the symptoms.

Yeah erm I think it's because it's, everything's from the inside out with PCOS. It's really hard to control anything that happens unless, unless you want to go on a contraceptive pill, which I don't. I think that's probably the only way that you control it. I've tried Metformin, I've tried, well that's it actually. I've tried Metformin and it didn't work for me and erm that's why, that's why I feel I'm in no, I have no control over it whatsoever. I can be feeling really good and really happy and brilliant and then just get a whole load of spots and think and what is that about? It's really upsetting and I can feel really low and really depressed about it and my skin's looking great and I just don't understand it at all. It's horrible.

[Holly, 25]

Holly was not alone in describing changes she had made to try and control her PCOS. Each participant reported trying different medications or symptom management techniques to try and control or deal with their symptoms, including hair removal and skin care routines. This has been reported by several other studies (Crete & Adamshick, 2011; Kitzinger & Willmott, 2002; Snyder, 2006; Washington, 2005) and was also described by participants in Chapter Three.

Several women reported trying numerous ways to remove excess hair caused by PCOS including; shaving, plucking, waxing and epilating the hair. Hirsutism is common in women with PCOS; indeed it is the aetiology of approximately 70% of hirsutism in women (Archer

& Chang, 2004). Looking for hair and removing it often formed part of the participants' daily routine as described by Kay, Tanya and Marie respectively.

I have to (?) and shave erm my hair...it's more tweezing and the shaving really, I do that almost daily. So that's quite draining doing it every day... [Kay, AU]

I get up, every day I have to, rather annoyingly, shave my face. [Tanya, 39]

I tend to epilate a lot, erm use hair removal cream, erm but that's frustrating as well because hair removal cream's really expensive and epilating hurts like hell [Marie, 20]

Similarly, Sharon details the hair removal routine she used to do before having children, below.

I think the facial hair was my big, big problem. I hated that and I used to spend an hour a day in the, in the bathroom with a pair of tweezers trying to pull it out and I think boyfriends in the past, a lot of them didn't even know I had it...I was just very good at getting rid of it.
[Sharon, 41]

In the quotes above we can see how participants felt that they needed to manage their symptom of hirsutism each day despite it being 'draining', annoying or 'frustrating'. Similarly, Kitzinger and Willmott (2002) describe how women with PCOS had a daily hair removal routine. This was also evidenced by Washington (2008) who found that participants shaved or plucked hairs daily. Moreover, Snyder (2006) reports that to control symptoms of hirsutism, every participant in their study invested time and money into treatments, including similar methods to participants in this study. Crete and Adamshick (2011) also reported the importance to their participants of controlling their PCOS symptoms through self-treatment.

Participants had similar routines for other symptoms including their skin care. This included checking their skin daily for any blemishes or acne caused by PCOS. Holly described this in the quote below; she also stresses how her symptoms are never stable.

So the first thing that always crosses my mind is what does my skin look like today?... I have like three weeks of the month where it is just horrendous and then you have a week where it

starts to clear up and you think ah (sic) maybe this is it and you think it is getting better now and it doesn't, it just improves for a week or so. [Holly, 25]

Hsu (2013) suggests that women with PCOS may experience changes in their PCOS symptoms with age, particularly in adolescence and later life. Consequently, health care professionals should be considerate of these changes in presenting symptoms in women with PCOS and offer appropriate support and guidance.

4.4.2 CO-MORBIDITIES

All the participants experienced one or more co-morbid conditions. The physical conditions were varied and include migraines, irritable bowel syndrome (IBS), hypermobility syndrome, hypothyroidism and adrenal fatigue. Participants also experienced depression and depressive symptomology. Holly was also in the process of being diagnosed for endometriosis, in addition to her other co-morbidities

4.4.2.1 Living with Other Conditions

Six of the participants (Holly, Tanya, Kay, Sharon, Emma and Dawn) discussed how they lived with other physical conditions as well as their PCOS. In the quotes below Tanya describes how she has IBS as well as PCOS. Interestingly, despite experiencing two long-term health conditions, Tanya states that she and her family 'don't really suffer from anything'. She goes on to describe how she lives with having two conditions and explains that she has to be 'careful with it'. The quotes below suggest that for Tanya, she identifies as being well, rather than 'poorly' even with her PCOS and IBS symptoms.

We've never really, we're not really like a poorly family. We don't really suffer from anything. Mmm I do get a lot of colds, I always pick everything up. Oh and I do have a, I've actually just realised, a touch of IBS. [Tanya, 39]

Yeah, I have a touch of IBS, it's one of those things that I know what sets it off and I'm just careful with it. [Tanya, 39]

To date only one article has explored the prevalence of IBS in women with PCOS. Mathur et al. (2010) found that not only were women with PCOS more likely to have IBS than healthy controls, but that women with PCOS and IBS symptoms were more likely to have a higher BMI and body fat percentage compared to women with PCOS but who did not suffer from

IBS. In the current study only Tanya reported experiencing symptoms of IBS; however, this finding does demonstrate a need for further research exploring the prevalence, and experience of IBS in women with PCOS.

Tanya's experience and the way she describes her co-morbidities contrasts with Kay who had several other conditions in addition to PCOS. In the quotes below Kay discusses how she has asthma, eczema and hypermobility (hypermobility is a condition where people experience loose or supple joints that can often result in pain). She explains that she has 'quite a bad time with them', suggesting she finds it difficult living with multiple morbidities.

I have erm asthma, erm I have eczema and I also have hypermobility erm which is basically from the double jointedness [sic] erm and I have a lot of problems with my joints, especially my knees erm and I have quite a bad time with them. [Kay, AU]

She continues to discuss how she lives with having PCOS and the other conditions explaining that you 'just have to...deal with it' and 'get on with it'. Kay also demonstrates a pragmatic attitude towards living with her multiple conditions, describing how she makes 'the best' out of her condition.

Think you just do, you just do, you just have to erm deal with it as it comes erm and get on with it. It's there and there's not much you can do to change that and you have to make the best out of the situation that you've been handed I suppose. [Kay, AU]

However, later she adds to this, describing how she can 'deal' with the eczema and asthma but that she feels her hypermobility impacts on her life. This suggests not only that the individual conditions may impact Kay's life in different ways, but that she perceives her ability to cope with the conditions differently as well.

The eczema and the asthma I can deal with that, that's fine erm it's, the hypermobility does affect your life erm and I'm a full time carer for my partner as well so I have to be careful with what I'm doing with that. [Kay, AU]

The quotes above from Kay help to demonstrate how women with PCOS may often be struggling to live with not only PCOS but other debilitating disorders as well. Sharon (in the

quote below) similarly describes how when living with PCOS and other conditions, in this case hypothyroidism, you have to just ‘accept’ it suggesting that women with PCOS and other conditions feel they have little control over their conditions and must simply ‘live with it’. Sharon describes how she thinks her conditions are linked together, but she has learnt to live with them and accept the situation despite the negative physical impact. Sharon also states that in order to live effectively with her conditions you must ‘adjust your life’ without ruining your life. This suggests that in order to cope with her co-morbidities it is necessary to change and find a new balance. This reflects the findings of the previous theme, *Changing Nature of the Condition*.

I think they are linked together to be honest erm I've got an underactive thyroid which is incredibly common amongst women who've got polycystic ovaries erm and I've got a couple of other medical conditions erm which, which all roll into make me feel tired all the time really. Erm but you get to, you get to live with it erm you know, it's a bit frustrating sometimes, you know, sometimes you'd like to have 48 hours in the day to get stuff done but you just gotta [sic] accept that you're gonna be tired and, and that's the end of it really. You just gotta [sic] erm adjust your life to your medical situation without making it ruin your life if you see what I mean. [Sharon, 41]

It has been suggested (De Ridder, 2004; Friedman, 2002) that individuals experience two phases after diagnosis of a long-term condition; the crisis phase whereby individuals may experience depression and anxiety, and the adaption phase where De Ridder suggests that individuals make an attempt to adapt to their condition and argues that most individuals will adjust to their new situation. This reflects the quote above where Sharon discusses ‘accepting’ her condition and adjusting her life to living with the condition.

Crisis Theory (Moos & Schaefer, 1984) similarly purposes that physical illness can be considered a crisis due to the consequential changes in identity, role, social support, future and location. Whilst women with PCOS are unlikely to experience a change in location as a direct result of having PCOS, they may experience a change in the other domains such as their identity as someone with PCOS (identity), and their future (becoming a mother). In order to cope with this crisis, Moos and Schaefer argue that individuals go through three processes: cognitive appraisal, adaptive tasks and coping skills. As part of the coping process, individuals may need to accept their situation and redefine it in a positive way, as

demonstrated in the quote above by Sharon. Charmaz (1997) similarly suggests that there are four ways that an individual accepts illness, they may: ignore it, struggle against it, reconcile themselves to it or they accept it. The quote above by Sharon is reflective of the latter two types of acceptance in that she has decided to ‘live with’ (p.47) her illness by acknowledging it and accepting it.

Carr, Gibson and Robinson (2001) suggest that when an individual’s expectations and experience are matched, or more simply they accept their condition, then the impact of the condition on quality of life is reduced. Moreover, Schüssler (1992) suggests that an individual’s ability to control their illness, and acceptance of it, are associated with problem-related coping rather than emotion-focused coping, which was associated with those individuals who did not accept their condition. Acceptance has also been shown to be related with coping in women with breast cancer (Lauver, Connolly-Nelson & Vang, 2007). In addition, Stanton et al. (2000) found that participants, who accepted their breast cancer, reported enhanced quality of life. Women with PCOS who accept their condition may therefore be better able to cope with their condition, and increase their quality of life.

Although there has been no research that explores PCOS and hypothyroidism specifically, research exploring autoimmune thyroiditis (AIT: the cause of hypothyroidism) suggests that there is a threefold higher prevalence of AIT in women with PCOS (Janssen et al., 2004). Similarly, Sinha et al. (2013) argue that there is a high prevalence of thyroid disorders in women with PCOS. There is a need, therefore, for further research not only into the prevalence of thyroid disorders in women with PCOS, but also into the experience of women who live with both conditions.

The difficulty managing multiple conditions expressed by Kay was echoed by Emma who described how she found it difficult to manage her migraines and PCOS (through taking a contraceptive pill) without one interfering with the other.

Well I’ve given up the erm contraceptive pill entirely which is a pain to be honest erm but I get migraines as well so it’s a bad combination because I can’t take the combined pill because of the migraines and I can’t take the mini pill because they’re progesterone only and then that interferes with the PCOS. [Emma, 25]

Like Sharon, Holly (in the quotes below) also felt that her co-morbidities were linked as she states that her adrenal glands and PCOS ‘go hand in hand’. She develops this later in the interview by stating that she has ‘adrenal fatigue which is linked to PCOS’ and that she also, like Sharon, has hyperthyroidism. However, there has yet to be research exploring adrenal fatigue and possible links with PCOS.

I think erm the adrenal glands and the PCOS go hand in hand and because I just feel knackered all the time now erm I, I think that the adrenal fatigue, depletion of the adrenal gland that usually coincides with PCOS, so yeah. [Holly, 25]

I’m being investigated at the moment for endometriosis erm I also have adrenal fatigue which is linked to PCOS and em quite a low thyroid count. I don’t know what you call it, hyperthyroidism. [Holly, 25]

Dawn describes below, how she discovered that she had a blocked fallopian tube, when attending a general appointment to discuss the possibility of IVF treatment.

Yeah and it was quite a shock because it looks like one of my fallopian tubes stopped working as well. So I went into perhaps go and have erm IVF and I went and had a scan with a, well they inject a dye into my tubes and erm one of them wouldn’t even go up and it was a hell of a shock just to find out well one of your tubes is now not working at all and you’re not producing erm the eggs you need and erm all this all down to this, this polycystic ovary syndrome...it was very devastating at the time, now I look back on it, it was. [Dawn, 36]

Dawn describes how she feels that the problems with her fallopian tubes were due to PCOS. However, there is no research in the area to support or oppose this claim. She adds that it was a ‘hell of a shock’ and ‘devastating’ to learn that she had another condition, in addition to her PCOS, suggesting that this was a traumatic experience for her. This demonstrates that women with PCOS and a co-morbid condition may find it difficult to cope, particularly at the time of diagnosis of the additional condition. To date; no research explores the experience of living with PCOS, and of being diagnosed with, one or more other conditions. As such, research of this nature would aid understanding of how women with PCOS experience living co-morbid conditions and the impact this may have.

4.4.2.2 Depression and Self-harm

Six participants (Dawn, Kay, Julie, Marie, Debbie and Tanya) in this study reported experiencing depressive symptoms which for some included self-harm. This has not previously been reported in any published qualitative research with regards to the experience of PCOS. Quantitative research has shown that women with PCOS report more depressive symptoms (Himlein & Thatcher, 2006) and a higher prevalence of depression (Cipkala-Gaffin et al., 2012; Hollinrake, Abreu, Maifeld, Voorhis & Dokras, 2007) than controls even after accounting for BMI and age (Deeks, Gibson-Helm, Paul & Teede, 2011), but findings from the present study show that for some women this may be more severe.

The relationship between PCOS and depression was discussed by Kay and Marie in the quotes below. Kay suggests that her depression 'is led from' her PCOS suggesting that rather than her depression being a result of a biological cause, such as polycystic ovaries, Kay sees it as a result of living with the symptoms of PCOS. Conversely Marie states that it is her PCOS that adds to her depression.

'cause I don't, for me polycystic ovaries doesn't create my depression, my depression is led from the aspects of polycystic ovaries [Kay, AU]

I wouldn't have thought the depression would impact the PCOS really but I suppose it could, I haven't really thought about that but definitely having the PCOS adds to the depression because of all the things you hate about yourself makes it diff, harder [Marie, 20]

Julie similarly had trouble defining what PCOS was, and what depression was, when discussing getting irritated with her daughter. Julie also touches on how this then impacts her relationships with others, in this case her family, demonstrating how having PCOS can also have an impact on the individual's relationships with other, overlapping with the theme of *Relationships*. Julie also speculates on the relationship between her PCOS and depression, suggesting that they be intertwined, with one impacting the other and vice-versa.

I don't know whether that's the PCOS or whether that's the depression or whether that's depression 'cause of PCOS but dealing with that and then the feelings of guilt that come with that, I think that affects me and then that effects how I am with everybody else. [Julie, AU]

Debbie also discussed her PCOS and her depression in the quote below. Similarly to other participants she was unsure about the relationship between the two and whether one affected the other or vice versa. This suggests that participants are not receiving adequate information regarding their conditions from their health care professional and as such are unable to get the appropriate care for them (Percy et al., 2009).

I think I just get on with it really but erm yeah I do sort of prioritise the depression but erm yeah I, I really don't know if that helps though with the PCOS and if it stems from that so it's helping the depression as well. [Debbie, AU]

Two of the participants in this study reported that they had or would self-harm. Currently there is no published research reporting the incidence of self-harm in women with PCOS. Dawn describes how she will self-harm when she gets 'hormonal surges'.

I, I think I get an over, an overload of testosterone because my whole attitude changes and it's really unpleasant for my husband and my family when I go through this, I think, a hormonal surge...I will self-harm when I get this. [Dawn, 36]

When discussing how she deals with her PCOS Marie also admits that she has a history of self-harm. She describes how she still thinks about self-harming and the impact PCOS and her depression have on one another; she suggests it is 'a cycle' between her depression and her thoughts about her PCOS.

Well I don't think I deal with it very well because erm I have a history of self-harming which got quite bad at one point erm I don't do it anymore but it's always still in my mind so when I have a really bad day I always still think about doing it. Erm and when, if I'm depressed about PCOS my thoughts can sort of go round and round and switch between all the different things that PCOS is doing and the depression is doing and it's all just a cycle really as when I do get really depressed it's hard to get back out of it. [Marie, 20]

Tanya (below), also described depressive symptoms, she explains how on 'really, really blue days' she would begin to think about 'ending it' but that thinking of her family and the impact it would have on them helps prevent her from following through with these thoughts. Similarly, Charmaz (1997) suggests that individuals who are experiencing long-term illness

may become immersed in their illness, and that continued immersion in illness may lead individuals to contemplate whether they should continue to live at all.

I had suffered some days where I was so depressed and so down I wouldn't leave the house, some days I wouldn't go out to buy food because I was just so miserable and so fed up and there are times that you, not that, you just have these really, really blue days where you just think 'Oh God, I'd love to just end, end it all as in, not, I'm finding it hard to explain it. I realise by ending it you would obviously end your life but I feel like if my body just stopped working. If I just shut my body down and it will all stop and it will stop doing this and it will stop doing that, but then obviously I just think to myself it's a selfish way of thinking. I'd never do that. I'd never go down that route because it's not fair to bring the stress to your family and also again it's that whole thing of being erm, not trying to be negative about it.

[Tanya, 39]

Tanya also mentions in the quote how 'some days' she 'wouldn't leave the house' or 'go out'. She was not alone in this; Kay and Emma (below) similarly reported isolating themselves in this way, demonstrating how these feelings have a substantial impact on their behaviour.

You know I don't go out. I think that erm someone might spot some hair or something then I'll make sure that's gone first... erm and it just, it kind of feels a lot like erm difficult to go out I suppose. It's just hard to take sometimes. [Kay, AU]

It does inhibit me slightly erm so it, I just, it'll, I will avoid situations because quite often I just feel very, very frumpy with it. [Emma, 25]

Percy et al. (2009) found that women with PCOS in their study also reported feelings of social isolation, as did Washington (2008). Kitzinger and Willmott (2002) similarly report that women with PCOS in their study would restrict their activities because of their hirsutism symptoms. Research suggests that social isolation, or loneliness, may predict changes in depressive symptomology (Cacioppo, Hawkley & Thisted, 2010). As such, further research is necessary to explore the relationship between social isolation and depressive symptoms in women with PCOS.

4.4.3 SUPPORT

4.4.3.1 Health Care Professionals

Similarly to the findings of Chapter Three, participants in this study described a sense of frustration due to lack of support, from their health care professionals. Every participant in this study conveyed ‘frustration’ over the support, or lack of support, which they received from their health care professionals. Several women expressed having to ‘push’ for tests to diagnose their PCOS after they presented at their doctors with symptoms. This is illustrated by Dawn in the quote below who presented with symptoms of hirsutism and infertility.

I think I became a right pain in the butt to the, my doctors because I kept going on ‘I think something’s not right’, you know, erm and obviously they just, they just kept fobbing (sic) me off. You know, ‘you’ll grow out of it’, erm and I think it was, it was because I started getting erm like quite a heavy moustache on my top lip....I couldn’t fall pregnant after six months that they actually put me through for a scan. Erm so, yeah so then I reckon yeah it’s when they found out that I had the little string of pearls going on [Dawn, 36]

Kitzinger and Willmott (2002) also found that participants in their study felt frustrated about delays in diagnosis, perceived health professionals as unwilling to take symptoms seriously, and felt that there was a lack of information provided by health professionals. Holly, in the quote below, describes a similar experience of having to push her doctors to send her for the correct tests to diagnose her PCOS.

Erm I, I think that, thank God I’m not a hypochondriac ‘cause I was really pushing for the test and pushing you know I knew there was something wrong, I knew I wasn’t right and erm doctors will make you think like, you’ll feel like you’re making it up, like it’s some great big mystery of the female reproductive system and er you know all these symptoms are in your head. [Holly, 25]

Emma also discusses below how she felt she was not taken seriously by her health professional when she sought a diagnosis. She stresses that had she not been ‘strong willed’ she may have believed that she did not have PCOS despite experiencing the symptoms.

Erm I think, well I found it fairly upsetting that she wouldn’t believe me when I knew what Helen was and I think if I had not been strong willed the way I am, I could very easily have

been convinced it wasn't true erm so it was a bit frustrating when it was, was very obvious to me erm that the doctor didn't seem to take my, she, she was determined it couldn't be that and sort of you couldn't get any, couldn't get her to think any further past that. [Emma, 25]

Holly also describes how her doctors made her feel like her symptoms were not real. She discusses how she saw several GPs before she was able to take the tests to diagnose PCOS.

I saw a doctor and he said I'll treat you as if you have got PCOS but I'm not going to do any tests and, and this wasn't good enough. So I went to another GP and she said 'no absolutely, let's do your tests' erm and it just strikes me that doctor's, GPs especially just don't really know anything about PCOS. It's really odd to find someone that knows as much as me about it which is really disheartening and really frustrating [Holly, 25]

Emma similarly describes how she had to visit more than one healthcare professional to get a diagnosis of PCOS.

it's pot luck who you get because my first doctor, my first GP was absolutely shocking, she was a nightmare and then surprisingly I went back the next time, I saw a young male doctor and he was completely different [Emma, 25]

This experience of visiting several health care professionals before getting a professional diagnosis appears to be a common problem for women with PCOS as Crete and Adamshick (2011) also reported that women with PCOS in their study felt frustrated by the need to see several health care providers to get a diagnosis of PCOS. Similarly, participants in a study by Snyder (2006) expressed frustration over the diagnostic process, with participants reporting several changes of health care professional before receiving answers. Washington (2005) also reported that participants with PCOS expressed disappointment in the lack of knowledge of health care professionals and did not receive a diagnosis for many years.

In the quote below Sharon explains how she believed she had PCOS for ten years before she received a diagnosis despite visiting several GPs with symptoms of PCOS.

Erm, I thought I had it for about 10 years before I was diagnosed. I went to a variety of GPs with weight gain, menstruation problems, hair in places I didn't want it erm and I was

always pushed away. “Oh your testosterone is OK”, go away, basically. It’s just women’s problems. Erm, and then I got myself a really good GP in London and he had a particular interest in Polycystic Ovaries and he said that even though my bloods come back normal it didn’t mean that I didn’t have it and he sent me off for an ultrasound and sure enough there it was. So, erm, I was lucky to be in the right place at the right time really. [Sharon, 41]

Relatedly, Sharon states that she was ‘lucky’ to get a diagnosis, rather than a diagnosis being something that she ought to have received after presenting at her local health care professional with symptoms of PCOS. In the quotes below Tanya and Dawn also describe how they had both experienced symptoms and visited health care establishments for ‘years’.

It’s only recently that someone’s actually said to me it’s going to be PCOS erm based on symptoms that I’d gone to the hospital with, for years now. Erm but I think it’s when one of the doctors come back to me and said ‘yes, it’s now PCOS’. [Tanya, AU]

Erm it was erm, I think, the doctors first started noticing something was wrong with me when I was about 13 and I didn’t get official diagnosis until I was about 22. So yeah, that’s how I got to know about it. [Dawn, 36]

Participants continued to feel unsatisfied with their health professionals after receiving a diagnosis of PCOS. Several participants described how their doctors or specialists did not provide adequate information at the time of diagnosis or thereafter. In the quote below Kay describes the time she was diagnosed with PCOS and was left with little information from health care professionals.

I was confused, really confused...I’d never heard of it before and I was pretty much just given a leaflet and kind of sent on my way...I was just really confused and baffled about what I’d got. [Kay, AU]

Previous research has similarly reported that women with PCOS claimed that although diagnostic tests may have been provided, health professionals failed to provide any information on the development of their PCOS or the condition itself, leaving the women with uncertainties over their condition (Crete & Adamshick, 2011). Likewise Snyder (2006)

reports women with PCOS in their study felt that not enough information was made available to them by their health care professional.

Marie similarly experienced a lack of information at the time of diagnosis, and how due to a lack of impact on her life at the time, she did not understand the condition fully. This quote also reflects the theme *Changing Nature of the Condition*, whereby participants PCOS symptoms change over time.

I didn't know what it was so at the time I just sort of, because it didn't really affect me too much at the time, I just sort of thought it was something small

Marie continues to describe how she felt frustrated when she was diagnosed at a young age as she did not understand her condition and, therefore, put full trust in the doctors ultimately leading to Marie receiving the wrong treatment. Marie states in the quote below “I didn't know what to ask him for”. This suggests that she needed more information and support in order to ask the doctor for specific help with her condition.

I was diagnosed earlier but also it's quite frustrating sometimes cause obviously I was growing up and I didn't understand it much so I was just doing whatever the doctors told me and they weren't very good at all cause I used to go to erm the children's unit...and the doctor I had there was really bad because he put me on the contraceptive pill and then its, the next time I went they took me straight off it saying I should never have been put on it because I was too overweight but he was the one who put me on it. So that was really frustrating, I just didn't know what to do, I didn't know how to help myself. I didn't know what to ask him for. [Marie, 20]

Participants in Crete and Adamshick's (2011) study also stated that they did not know what questions to ask their health professional at the time of diagnosis. Moreover, Barry, Bradley, Britten, Stevenson and Barber (2000) found that only four of 35 patients in their sample discussed everything they wished to with health care professionals in their appointments. This, they suggest, leads to patients needs not being addressed appropriately. Morgan (2008) also reports that patients are often passive and unquestioning during initial hospital consultations, but in later consultations they take a more participatory role.

Marie later continues to describe how she failed to discuss the 'list' of things she would like to discuss with her doctor.

I've always, whenever I go to the doctors I'll always sort of prepare a list in my mind of what I want to tell them about erm but when I get there I'm not, either I'm too embarrassed to say or I just think there's like too much to talk about and there's nothing that they'll be able to do and there probably is but I'll just, won't say anything erm so I'm very closed off with my doctors as well. [Marie, 20]

Ogden (2012) suggests that delays in help-seeking, exemplified in the quote above by Marie 'I...won't say anything', can undermine health care professionals as it makes it difficult for them to treat the problem. One reason people may delay seeking help from a health care professional is due to the cost/benefit analysis of going to the doctor (Ogden). This is exemplified by Marie in the quote above who did not discuss issues she wished to raise with her doctor, as she deemed there to be 'nothing' they could do to help. Quill (1989) suggests that lack of openness by health care professionals, can have a negative impact on data gathering and implementation of treatment in a health care setting. In modern day consultations, Ogden (2012) suggests the patient and health care professional are involved in a communication process. Furthermore, Bensing and Verhaak (2004) suggest that adequate communication is essential for effective 'doctoring'. However, they also propose that patients are more likely to disclose information to health care professionals who show empathy. As such, there is a need for health care professionals to encourage patients to express and articulate their needs in order to overcome communication barriers (Bensing & Verhaak; Ogden; Quill, 1989).

Holman and Lorig (2004) propose that with the rise of long-term illness both the patient and the health care professional have new responsibilities and roles that are not applicable to issues associated with acute illness. Specifically, health care professionals take the role of a teacher who will enable the patient to develop the skills needed to self-manage their condition over time. Therefore, both health care professional and the patient have new responsibilities: the patient has a responsibility to use medications properly, change behaviour to improve symptoms, and interpret their symptoms. Barlow et al. (2002) similarly suggest that health care professionals should take time to foster patients' self-management abilities and ensure they are maintained. Jallinoja et al. (2007) similarly found that health care professionals working with patients with long-term conditions (diabetes and hypertension) believed that

self-care and lifestyle related decisions were the patient's responsibility. As such, whilst the patient should be encouraged to be responsible for their own condition management, the health care professional should also provide a supportive environment which gives patients the skills to self-manage. Glasgow, Davis, Funnell and Beck (2003) differentiate this as a responsibility to the patient and not a responsibility for the patient.

This theme replicates the findings of Chapter Three whereby women with PCOS felt unsupported and frustrated by their health care professionals and the lack of information they provided. This suggests that health care professionals need to be more supportive of women with PCOS and that there is a need for them to recognise the impact of this condition, and co-morbid conditions, on the individual's daily life. However, women with PCOS must also engage in communication with their health care provide to allow for effective treatments and support to be given. Future research exploring these phenomena from a health care provider's perspective may help shed new light on this problem and how this may be improved.

4.4.3.2 Self-Support

Several participants in this research resorted to supporting themselves through researching and educating themselves about their condition due to a lack of information and perceived support from their health care professionals; these findings are similar to the findings of the Chapter Three theme *Education*.

Dawn describes below how she feels that when she was diagnosed, she was not given an adequate explanation, by health care professionals, about her condition. She also discusses how she feels she was just given a label of 'polycystic ovaries' and consequently, was left to research her condition and educate herself about PCOS.

It's just like we've got this, this label of polycystic ovaries and but there's not a lot of explanation and that was about, oh goodness me, that was about 15 years ago and it was up to me to sort of like try and research as much as I could on it. [Dawn, 36]

Marie, as mentioned in the theme *Health Care Professionals* above, describes how when she was diagnosed, at 14 years old, she was unaware of 'all of the effects' of PCOS. However, it was only through doing 'loads of research on it' that she became more aware of PCOS and the effects the symptoms may have. She also states that it did not bother her 'at the time'; this

suggests that the impact of PCOS, or relevance of the condition to a person, can change throughout an individual's life. This is similar to the findings of the previous theme, *Changing Nature of the Condition*.

I didn't know, obviously cause I was only 14, I didn't know what it was erm, so, at the time I just sort of, because it didn't really affect me too much at that time, I just sort of thought it was just something, small, erm, but then I did loads of research on it and found out all of the effects it has and its obviously now that I (?) a lot of the symptoms are a lot harder to handle now but erm, yeah, at the time it didn't bother me too much. [Marie, 20]

Holly also proactively researched her condition using books and the internet (blogs) after receiving a diagnosis which allowed her to create her 'own action plan' in order to be better able to manage her condition. She explains that although there is 'a wealth of information out there' this is not from health care professionals but from women with PCOS who are 'doing it themselves'.

So when I got the diagnosis it made me, you know, I could go out and read the books and read the blogs and come up with my own action plan; which I did...So it really does, there's such a wealth of information out there, but unfortunately it's not from the medical erm industry, it's from people doing it themselves, people who want to cure it naturally. [Holly, 25]

Later in the interview Holly goes on to discuss that doing her own research and trying new ways to manage her symptoms can become 'exhausting'. She also describes how if new methods do not work it can lead her to go 'back down to that low place', suggesting that the trial and error process which results from self-support methods, like research, can be trying on women with PCOS.

I do lots of research and I think oh I'll try this. I'll try something new and you kind of rally yourself to do new things and then you realise it's not going to work, it's not working then you go back down to that low place and then you've got to rally yourself up again to try something else and it's just, it's quite exhausting just always, I don't know. [Holly, 25]

Similarly to Holly, and to participants in Chapter Three, Tanya discussed how after diagnosis, she attended a conference on PCOS held by a UK PCOS charity and this helped her to manage her symptoms.

It's for me to go away now and, and try the creams and take the tablets and beginning to research it and go to conferences and things like that. [Tanya, 39]

These findings are similar to those of Snyder (2006) who found that women with PCOS actively searched for answers without the help of a health care professional. Similarly, Crete and Adamshick (2011) also found that participants in their study discussed formally searching for answers through the use of online resources and books, supporting the findings of this study which suggest that women with PCOS self-educate. This suggests that women with PCOS are not receiving adequate support from their health care professional and are instead seeking out health care information independently.

4.4.3.3 Relationships

Several participants found support and information from other women with PCOS by using online support groups available through social networking websites such as Facebook. This reflects the findings of Chapter Three of this thesis.

Holly found support from women with PCOS online, as described in the quote below, claiming that they have 'more knowledge' than her family, are 'more understanding' and 'so supportive'. The quote demonstrates how although Holly's family were 'supportive' they were unable to 'understand' her condition in a way that other women with PCOS could. This suggests that using support groups of this kind can help reduce feelings of loneliness or isolation in women with PCOS.

I think erm these women have er more knowledge than my family about it and they're more understanding. My family are supportive but they don't understand it at all. Even my sister whose got PCOS, she has, she hasn't really got any symptoms other than a bit of excess hair. She's never even researched it because she doesn't feel she needs to but these women online, they've done so much research and, and they're so supportive. [Holly, 25]

This concurs with Holbrey and Coulson (2013) who found that participation in an online support group for women with PCOS can help women feel empowered as it allows them to connect with other women with the condition and enables them to access information and advice. Percy et al. (2009) also found that women with PCOS who took part in face-to-face support groups valued the opportunity to gain information from the group.

Tanya, as mentioned in the sub-theme *Self Support*, found support in the form of relationships with other women with PCOS through conference attendance.

I went to a conference...there were so many other women there who were in exactly the same position as me...It's very reassuring, as I don't feel like I'm alone. I feel like there are people I can talk to other than my husband and friends and family and like I can actually identify with something. [Tanya, 39]

Tanya also described the support she receives from her husband (in the quote below) particularly when she does not feel confident or feels paranoid that other people may see her symptoms.

My husband, God, loves me more than anything and he is the most understanding thing towards this...He's so wonderful about it...if he knows that losing weight will decrease symptoms and make me feel a happy person: he's all for it, I think he will do anything. [Tanya, 39]

Other participants described the support they received through relationships with female family members. For example, Emma discussed how through discussions with her mother and her cousin who also has PCOS, she decided to visit a healthcare professional.

My mum, 'cause my cousins got it [PCOS] and my mum independently had a conversation with me because we assumed that actually that might be what's happening...and then my cousin saw her, she told my mum separately 'I think Emma's got PCOS' [Emma, 25]

Later in the interview, Emma refers to her cousin's experience of PCOS and how this helped her feel less anxious about being diagnosed, and she also discusses how she will speak to her cousin about her PCOS.

I knew what it was so I wasn't anxious about getting the results [Emma, 25]

Every now and again my cousin will have a talk; we'll chat about it [Emma, 25]

Holly also describes her experiences with her mother and the support she received from her. She describes how her mother 'gets the brunt of it' partly because of the familial relationship and also because her mother is a nurse, and therefore, arguably more knowledgeable about PCOS. In contrast, Holly (below) describes how her husband 'doesn't understand it in the slightest' but that he 'bears the brunt' of her mood swings and complaints about the symptoms of PCOS.

Erm yeah I think for me it's been a long, long road of getting diagnosed, now still I don't particularly feel anywhere near the end of my journey if you like. Like with being happy with having PCOS and my mum especially gets the brunt of it because she, well she's, she was a nurse and she's my mum. She understands and she's there to listen to me erm but I, I do moan to her about it quite a lot and my husband doesn't understand it in the slightest but he bears the brunt of my bad moods and you know if my skin is really hurting one day, he'll get it in the neck for about half an hour while I moan about it. [Holly, 25]

Washington (2008) also reported that participants with PCOS found that their mood swings had an impact on their relationships with their spouses and family members.

One participant, Marie, described how in her current relationship her partner was unaware of her PCOS and how this had caused 'problems' for her and led her to feel 'insecure' about her body, consequently she would not allow him to touch her 'in certain places'. However, in her past relationships, Marie describes how she was 'open about' her PCOS 'straight away' and this enabled her past partners to 'understand'. This suggests that for Marie it was difficult to talk about her condition to her partner, which may lead to her feeling isolated or withdrawing from the physical aspects of their relationship.

Erm, well I've only had 3 relationships and the first two it didn't affect them as I was very open about it straight away and I said I've got PCOS which is this and they understand but the relationship I'm in at the moment it is causing problems for me because I've, for some reason I haven't got round to having that conversation of letting him know that I've got it so

I'm still really switched off and insecure about my body, I won't take my clothes off in front him and I won't let him touch me in certain places. [Marie, 20]

Friedman (2002) describes this situation, where an individual with a long-term condition where the symptoms are not visible to other people chooses not to disclose their condition, as 'passing' (p.197). Charmaz (1997) defines passing as 'functioning without detection of either the illness or its effects' (p.66). Certainly, Friedman suggests that when a person engages in passing, it can cause anxiety when the time comes for the individual to reveal their condition to another comes. In addition, Friedman suggests that passing can cause anxiety for the individual as it may lead to them questioning whether they will be accepted once they reveal their condition, as is demonstrated by Marie in the quote above. This also reflects findings of the theme *Relationships* in Chapter Three.

These findings suggest that women with PCOS may become isolated or withdraw from their relationships, although some of the participants in this study were open about their condition and felt supported by their families and partners. In this study the women also found support from other women with PCOS and deemed this to be a unique level of understanding and awareness of their condition. There is a need, therefore, for further research which explores the different relationship dynamics women with PCOS may have in order to gain a better understanding of how they experience these differing relationships. This is supported by, and builds on, the findings of Chapter Two.

4.4.4 IDENTITY

4.4.4.1 Feminine Identity

Six participants (Tanya, Dawn, Emma, Julie, Marie and Kay) discussed their PCOS in relation to their identity as a woman. Washington (2008) similarly found that for women with PCOS the condition could have a negative impact on their self-concept including their self-image and their femininity. This is also supported by the findings of Chapter Two; many women with PCOS perceive themselves as unfeminine.

In the quote below Tanya describes how instead of feeling 'sexy' or 'attractive', because of her PCOS, she feels like a 'man'. She states that she feels 'like a freak' because of her PCOS and its symptoms, suggesting she thinks she is abnormal because of her condition. Kitzinger

and Willmott (2002) also found that their participants described themselves as a 'freak' because of the symptoms of their PCOS such as hirsutism.

I think, as a woman, you, you want to feel sexy. You want to feel attractive to the opposite sex.

I think when you have these problems, you don't. You feel like a freak. You feel like a man.

[Tanya, AU]

A number of women talked about having masculine attributes due to symptoms of PCOS, threatening their identity as a woman, as demonstrated by Dawn and Emma in the quotes below. This is supported by the findings of Chapter Three whereby women with PCOS can see themselves as unfeminine, often using male language and terminology to refer to their PCOS and its symptoms.

I've got a very good sense of humour about it because sometimes I swear I'm just like one penis away from turning into a guy. [Dawn, 36]

It's always at the back of my mind that I'm waiting for the day when one of them is drunk and particularly aggressive and mentions it erm and makes some comment along the lines of bearded lady or God knows what they'd do. [Emma, 25]

Marie also describes how her PCOS symptoms, in addition to having smaller breasts, make her feel 'less of a woman'.

'cause of not having periods and hormones being all screwed up, I've never really developed any breasts. So now at the age of 20 I fell it's another thing on the list of things that make me feel less of a woman because I don't have breasts and I'm hairy and erm so that's another thing that gets me depressed [Marie, 20]

This impact of PCOS on feminine identity has been identified in the literature a number of times. Washington (2008) describes how their participants felt that PCOS negatively impacted on all areas they associated with being a woman because of the symptoms of PCOS such as obesity, hirsutism, alopecia and infertility problems. Snyder (2006) also found that women with PCOS felt that their symptoms impacted on their perception of themselves as female. Snyder reported that women with PCOS wanted to be normal and look more

feminine. Castillo (2008) also described how women with PCOS in their study did not like feeling like less of a woman because of their PCOS. Moreover, Kitzinger and Willmott (2002) found that women with PCOS felt challenged in their perception of themselves as women because of their symptoms. Several participants in this study also considered themselves as not 'real women' or as broken due to their PCOS and its symptoms, particularly infertility.

Julie felt that she was not 'a real woman' because she found it difficult to breast feed her baby, which she felt was due to the symptoms of PCOS.

Erm but that, that again, that was something it was like oh well you know a real woman would be able to breast feed their baby, I mean that's what you have babies for is to be able to feed the child and I can't even do that and erm I beat myself up with so many polycystic ovaries sticks. [Julie, 36]

Kitzinger and Willmott (2002) similarly describe how women with PCOS in their study found their inability to conceive differentiated them from other women. Later in the interview Julie (below) again described how she felt like she 'wasn't a real woman' because she struggled to conceive due to her PCOS. This led her to self loathe which she believes was then 'exacerbated' by the difficulty she found in feeding her child. She describes how she felt 'utterly inadequate' and 'a waste of space' because she found conceiving and feeding her child difficult and felt that 'everyone else can do it'. This quote demonstrates how women with PCOS can compare themselves to other women and perceive themselves as having less worth because of their condition and its impact on their life. Negative upward social comparison, in this case to women perceived as being 'normal', has been shown to be negatively related to quality of life and to have a negative impact on adjustment to long-term conditions (Dibb & Yardley, 2006).

I just sort of feel like well I obviously wasn't a real woman because I couldn't do the children bit erm and, yeah, I think there was quite a lot of self-loathing going on really erm and then that was, that was sort of exacerbated when I couldn't feed her myself. Erm, that again it was just, just feeling utterly inadequate. I mean inadequate isn't even a good enough word to describe how inadequate I felt. Erm, yeah, I mean literally it was just feeling like just, just a

waste really, a waste of space because all these things that mentally you're saying everyone else can do it. [Julie, 36]

For Julie, her difficulty having children led her to see herself as 'less of a person' and 'not a real person', demonstrating the impact that having PCOS can have on an individual's perception of self.

I think Rob probably does, not in, not in the way that I did which was I'm less of a person and I'm not a real person cause I can't have, you know, procreate [Julie, 36]

Dawn similarly did not 'feel very womanly' because of her difficulty to conceive. She describes how she feels that women are 'designed' to have children and 'look feminine', and how the PCOS symptoms of hirsutism and alopecia do not allow for this.

Well yeah I just don't function properly do I? You know I, I feel, I try not to think about it too much because otherwise you will flump won't you but I don't feel very womanly at all, you know erm, you know we're designed as a woman aren't we to have children, look feminine and not have hair sprouting from everywhere apart from the top of your head if you like. [Dawn, 36]

Tanya, in the quote below, also felt like there was 'something wrong' with her because of her PCOS. She describes how having the condition makes her 'feel like a freak'.

When there's something wrong with you like this especially, it's such a socially unacceptable thing to have, you do feel like a freak and you think you're the only person out there. [Tanya, 39]

Kay, similarly, feels like she is broken because some 'things that should come naturally as a woman' don't. She adds that because of her hirsutism and weight, her 'self-image' is low and, as a result, she feels like she is 'broke'. This suggests that PCOS can have a negative impact on a woman's self-image. Indeed, Washington (2008) also found that the participants in their study reported that PCOS had a negative impact on their self-esteem and self-image.

You almost feel like you're broke erm some of the things that should come naturally as a woman, don't and are never going to and erm so your self-image is quite low erm... weight and hair, confidence erm so that's quite hard at times. Erm yeah, it's, I was, I always kind of feel like you're broke. That's how I would explain it. [Kay, AU]

Likewise, Julie described herself as not working when explaining her inability to have another child to her daughter.

I just said erm "unfortunately sweetheart mummy's equipment doesn't work, so I can't" we always called it cooking; "I can't cook any more babies I'm afraid. So I'm afraid we won't, you won't be able to have a brother or a sister". [Julie, 36]

4.4.4.2 Us and Them

Several participants discussed how they felt it was 'unfair' that they had PCOS or its symptoms in comparison to other women without PCOS. As mentioned in the theme above, negative social comparison is related to decreased quality of life and can also have a negative impact on an individual's adjustment to a long-term condition (Dibbs & Yardley, 2006).

Certainly, Marie discusses how she will compare herself to her friends without PCOS and feel that it is unfair that they do not have symptoms as she does.

I live with my friends and I'm thinking, I'll look at their bodies and think, why aren't you hairy? How have you got such smooth skin? It's not fair. [Marie, 20]

Tanya, in the quote below, similarly feels that it is 'really unfair' that she suffers from PCOS and 'not' other 'people', questioning 'why' she has the condition. Similarly, research exploring cancer in women has reported that participants felt it was unfair that they had been diagnosed with cancer (Fitch, Godel & Labrecque, 2008) over other people, and questioned 'why me' (Taylor, Outlaw, Bernado & Roy, 1999). Kralik, Brown and Koch (2001) similarly found that when women were diagnosed with breast cancer they were initially shocked they asked 'why me?', however, as they came to terms with their condition and gained more information the shock subsided. This suggests that as individuals accept their condition, they are better able to cope with their diagnosis (de Ridder et al., 2008).

I do wonder a lot, why me? Why, why did I have to it and not, and not people? I don't know anybody else whose got it er and part of me does feel like my bodies let me down and, and it's really unfair. [Tanya, 39]

Holly also mentions that it is unfair when discussing PCOS in comparison to other women, particularly in relation to the fertility symptoms of PCOS. Previous research exploring the experience of infertility has also found that participants felt it was unfair that they were not able to have children (Cooper, 1993; Redshaw, Hockley & Davidson, 2007).

It's just, it feels really unfair. It feels like some women just sneeze and get pregnant...it's so unfair. I just don't know, understand why PCOS chooses some people and not others. [Holly, 25]

Holly also questions 'why' she has PCOS, as opposed to others, describing it as a 'horrible' condition. Holly also expresses frustration at the lack of information and 'explanation' about the causes of PCOS.

Like I said before, I always think why me? I think it's just such a horrible thing to have erm and there's no real explanation as to why you've got it which makes it so frustrating. [Holly, 25]

It's just time consuming and frustrating and I wish I could be like normal people who don't have to do this. [Tanya, 39]

I suppose you have to think more about things rather than when other people wouldn't really give, like other women and stuff probably wouldn't give thoughts to. [Debbie, AU]

Snyder (2006) found that women with PCOS identified themselves as different to women without the condition. Similarly, in the quote above Tanya demonstrates how women with PCOS may compare themselves to 'normal people' without the condition. Debbie also made comparisons to other women without PCOS. In accordance with the theme *Feminine Identity*, the participants made social comparisons that could have a negative impact on the quality of life and adjustment to the condition (Dibb & Yardley, 2006). Weiss and Bulmer (2011)

similarly found in their study exploring the experience of PCOS in young women, that participants identified themselves as different from women without PCOS.

4.5 Discussion

This research attempted to explore and gain an understanding of how women with PCOS in the UK live with and perceive their condition, and any co-morbid conditions on a day-to-day basis. A thematic analysis of the data produced four themes: Change (Change to Life Plans and Changing Nature of Condition), Co-morbidities (Living with Other Conditions and Depression and Self-harm), Support (Health Care Professionals, Self-Support and Relationships) and Identity (Feminine Identity and Us and Them). The themes of Support and Identity have been discussed previously in the literature (Kitzinger & Willmott, 2002; Snyder, 2006) and in Chapter Three of this thesis. However, this research is the first to explicitly explore women's experiences of living with PCOS and presenting co-morbid conditions on a daily basis.

This research is the first to report how women with PCOS perceive their condition as impacting on their life plans, for example, having children. Whilst this is the first study to discuss this phenomenon in women with PCOS, wider literature surrounding long-term conditions suggests long-term illness may jeopardise an individual's accomplishments of goals (De Ridder, 2004). This impact of illness on an individual's personal goals has been suggested to also have an impact on an individual's perception of their quality of life (De Ridder) due to the gap between what an individual hopes to achieve (in this study having children at a certain time) and their current situation (Calman, 1984). Furthermore, De Ridder suggests that this is due to quality of life involving the individual's subjective evaluation of their goals and their attainment. The impact of PCOS on the participants personal goals may therefore, have an impact on their quality of life.

Whilst not discussed previously in the PCOS literature, the impact of long-term conditions on future plans has been noted in other women's health conditions including endometriosis and diagnosis of the BRCA gene mutation (Denny, 2009; Moradi, Parker, Sneddon, Lopez & Ellwood, 2014; Smith, Ellington, Chan, Coyle & Botkin, 2004). Specifically, research suggests that women with endometriosis can be uncertain about their futures and their future fertility (Denny, 2009; Moradi et al., 2014). However, Young, Fisher and Kirkman (2014) suggest that there is still a paucity of research which explores the experience of infertility for

women with endometriosis. Similarly, research exploring the fertility intentions of women diagnosed with the BRCA1 Gene mutation found that predictive genetic testing for cancer susceptibility affects decision-making with regards to family planning (Fortuny et al., 2009; Smith et al., 2004). Prevention and treatments for cancer can also impact a woman's fertility (Werner-Lin, 2008). As such, women diagnosed with the BRCA1/2 gene may experience similarities to that of PCOS when considering the impact of the condition on the individual's children related goals.

Participants in this study reflected stages of adaption as proposed by De Ridder (2004): many of them discussed feelings in line with the crisis and adaption phases of adjustment to life with a long-term condition. That is that participants described being distressed as a result of their diagnosis and many of them experienced feelings of depression. However, many of the participants detailed how they had begun to adapt to their condition. For example, participants in this study engaged with adaptive tasks such as sustaining their relationships with family and friends, and preparing for an uncertain future (De Ridder). Whilst adaption to a condition is difficult to measure, de Ridder suggests one way that it can be measured is to assess quality of life. However, as noted in Chapter Two of this thesis, the existing PCOSQ (Cronin et al., 1998) is insufficient for measuring quality of life of women with PCOS and as such, Chapter Five will detail the development of a new quality of life measure for women with PCOS in the UK.

Many of the participants in this study experienced co-morbid symptoms, both physical (migraines, IBS, hypermobility syndrome, hypothyroidism and adrenal fatigue) and psychological (depressive symptoms and self-harm). Whilst quantitative research has demonstrated the prevalence of depression in women with PCOS (Bhattacharya & Jha, 2010), this study is the first to report how women with PCOS experience living with this condition and other co-morbidities such as depression. Over half of the participants in this study discussed depressive symptoms and self-harm however there is little discussion of self-harm in the quantitative literature (Hart & Doherty, 2014; Månsson et al., 2008). Further research is needed to explore the prevalence of psychological co-morbidities, including depression in women with PCOS in the UK. Furthermore, future research should explore the prevalence of self-harm in women with PCOS. In addition, a suitable intervention is needed which aims to decrease depressive symptoms in this population. Consequently, this thesis shall explore the

prevalence of psychological co-morbidities in women with PCOS in the UK (see Chapter Six).

This study highlighted that some of the women with PCOS in this study felt under pressure to have children. Holly particularly felt under pressure from her health care professionals, whereas Kay discusses the pressure of time on her ability to conceive. Overall, participants discussed the negative impact that feeling under pressure to have children had on their life plans (Williams et al., 2014). Whilst this has not previously been reported in the PCOS literature, Moradi et al. (2014) found that women with endometriosis received recommendations by health care professionals to have children at an early age. As research suggests that infertile women report poor quality of life compared to controls (Monga, Alexandrescu, Katz, Stein & Ganiats, 2004) and that they experience similar psychological symptoms to those patients with cancer, hypertension and cardiac rehabilitation (Domar, Zuttermeister & Friedman, 1993), infertility can arguably have a large negative impact on the women who experience it, without the perceived added pressure to conceive from a health care professional that Holly experienced. Thus, research is needed which further explores how women with PCOS perceive pressure to conceive, and how they experience conversations with their healthcare professional with regards to fertility and family planning. Moreover, research is needed which explicitly explores how health care professionals discuss pregnancy with women with PCOS and the impact of these conversations.

This study invited women with PCOS to take part in focus groups, and then in a face-to-face or online interview. In this way, the focus groups would have enabled further exploration of topics raised in the focus groups, in addition to those questions detailed in the interview schedule. However, potential participants were given the option of choosing whether to take part in both parts of the study, or just one, in the event that recruitment for the focus group was not successful. During recruitment potential participants demonstrated a reluctance to take part in the focus group aspect of the study, or the face-to-face interviews. As such, all participants took part in a one-to-one online interview. In general, participants did not want to travel or were unable to travel in order to take part in the focus group. Other participants were unable to attend a focus group due to work commitments, and consequently, each participant opted to take part in the online interview. To overcome this issue in future studies, researchers could consider using online technology which facilitates multi-person calls to conduct focus groups.

The use of Skype™ interviews in this study meant participants were easily able to take part, and the costs were minimal to both the researcher and participant. The online interviews may have allowed participants to feel at home, as evidenced by participant's behaviours, such as answering doors or watching their children, demonstrating minimal interference in their day-to-day lives. Participants in this study also discussed being socially isolated, as such, the online interviews allowed them to take part in the interviews (Janghorban et al., 2014). Had the interviews been in person or at another location, they may not have wished to take part. Whilst using Skype™ was a viable method for data collection for this study, there were issues with the technology itself (Saumure & Given, 2010) in the form of noise interference on calls which could have had a negative impact on the interviews and resulted in missing data. This study also used the audio only call option (the participants preference) available through Skype™; as such visual cues were not observed which may have limited the data collected in this study (Saumure & Given, 2010). Future research should explore the use of other online interview methods such as FaceTime for apple users and Google Hangout; this allows up to eight users to take part which could help facilitate online focus groups.

While providing an important account of women's experiences living with PCOS and co-morbid conditions as this study recruited participants from Facebook support groups, the participants were already seeking support from the online PCOS community. As such, the sample may not be representative of women who are not seeking support from other women with PCOS, or who are not seeking or utilising support from online sources. It is unclear what, if any, support participants received for their co-morbidities from either PCOS groups, or indeed other support groups on Facebook. Moreover, as the study recruited participants online, a clinical diagnosis of PCOS, or any co-morbid conditions cannot be guaranteed. Although previous studies have explored the prevalence of specific co-morbidities (including diabetes, hypertension, sleep apnea, anxiety, depression) in a population of women with PCOS (Bethea & Nestler, 2008; Sirmans, Parish, Blake & Wang, 2014), there remains a need for further research which explores the prevalence of clinically diagnosed co-morbidities in women with PCOS in the UK, specifically in relation to psychological co-morbidities such as depression and anxiety. As such, the study detailed in Chapter Six will investigate the prevalence of psychological morbidities in women with PCOS in the UK.

Dissemination of these findings could help increase health care professionals understanding of the condition, which was reported to be lacking by participants in this study, and the previous of chapter of this thesis. Moreover, dissemination of this study's findings could highlight important new areas of research, including: research into the prevalence of self-harm in women with PCOS and the prevalence of co-morbidities, exploration of how women with PCOS manage their condition with co-morbidities, exploration of the perceived pressure to conceive, particularly from health care professionals, and development of an intervention which may help reduce depressive symptoms in women with PCOS.

This study aimed to further understanding of how women with PCOS in the UK live with and perceive their PCOS, and any co-morbid conditions or symptoms, on a day-to-day basis. The findings revealed how women with PCOS may experience negative feelings when faced with changing their life plan as a result of their PCOS, particularly with regards to family planning. Moreover, the participants described how they found their condition unpredictable, meaning they had to regularly change their methods of self-management, including medications, daily hair removal and skin treatment routines. It also revealed how women with PCOS experienced living with co-morbid conditions, both physical and psychological. Similarly to Chapter Three, the findings of this study reflected the domains of quality of life as detailed by quality of life researchers (WHOQOL Group, 1994; Testa & Simonson, 1996). This included the domains of physical and psychological health, level of independence, social relationships and environment (WHOQOL Group). Consequently, the findings of both qualitative studies and how they will be used to inform the development of a new PCOS quality of life scale shall be discussed within the next chapter.

Chapter Five -Development of the PCOSQOL: A quality of life measure for women with PCOS.

This thesis aims to assess and find ways to improve quality of life for women with PCOS; it is therefore necessary to first ensure that there is a suitable way to measure the construct in a UK sample. As such, this chapter describes the development of the PCOSQOL, a quality of life measure for women with PCOS in the UK. This chapter also describes the testing of the validity and reliability of the PCOSQOL for use with women with PCOS in the UK, according to scale development guidelines (DeVellis, 2012; Streiner & Norman, 2008).

The findings of Chapters Three and Four suggested that social relationships were of importance to the participants. In both studies, the participants discussed a range of personal relationships, social support and sexual activity; mirroring the domain of social relationships reported by the WHOQOL Group (1994). Moreover, the participants discussed their symptoms and the impact they had on them, including pain, and fatigue; these map on to the physical health domain reported by the WHOQOL Group. The domain of independence (WHOQOL) was also highlighted within chapter three of this thesis in the theme *PCOS as Controlling* which reflected the participants' dependence on certain supplements or self-management routines. Many of the women in the qualitative studies described avoiding social activities and becoming socially isolated due to their PCOS, reflecting the environment domain. Moreover, in both qualitative chapters, participants discussed their body image and negative and positive feelings, reflecting the domain of psychological health (WHOQOL). The qualitative findings then suggest that PCOS can have an impact on all areas of quality of life. The development of the PCOSQOL therefore, aims to be inclusive of all aspects of quality of life that may impact women with PCOS (Malik-Aslam et al., 2010), including the physical health, psychological health, level of independence, social relationships and environment domains detailed by the WHOQOL group (1994).

As the PCOSQ (Cronin et al., 1998) pertains mostly to physical symptoms, it overlooks many of the aspects of quality of life raised by women with PCOS in this thesis, as detailed above. In 2012 the Amsterdam ESHRE/ASRM workshop argued that research in the area of quality of life in women with PCOS has been hampered by the existence of only one validated disease-specific questionnaire, the PCOSQ (Cronin et al., 1998). However, the PCOSQ has several problematic characteristics which were detailed in-depth in Chapter Two of this

thesis. These issues included development of the PCOSQ using an unrepresentative sample, a small sample size and inappropriate methods for item reduction. It was also developed for use within a US sample, rather than a UK sample.

5.1 Introduction

In 1998 Cronin et al. developed the 26-item PCOS questionnaire (PCOSQ) in the USA. Whilst Cronin et al. did not validate this questionnaire it was later validated by Guyatt, Weaver, Cronin, Dooley and Azziz (2004) and Jones et al. (2004): both Guyatt et al. and Jones et al. tested the reliability and discriminative validity of the questionnaire. The PCOSQ was the first, and until the development of the current measure, the PCOSQOL, the only disease-specific quality of life measure for women with PCOS. However, there are several issues with the development of the PCOSQ and its use in the UK. The first issue concerns the sample used to develop the items for the scale as the initial interviews were conducted with patients of three of the authors of the research, meaning that the patients were already in the US health care system and getting professional help. However, the participants in the qualitative studies of this thesis (Chapter Three and Four) suggested that they were not receiving support from healthcare professionals. For example, Lucy stated that ‘Doctors were asked about it [her PCOS], and they referred me to Waterstones’. In addition, Dawn described how she would ‘avoid’ visiting a doctor if she could. This suggests that the items developed are unlikely to be representative of women who have been discharged from the health care system and may not be receiving ongoing support from their health care provider.

In line with this, there is a second issue concerning the participant sample and its recruitment from the authors patient pool in that the USA has a different health care system to the UK (Ferlie & Shortell, 2001; Schoen et al., 2004); women with PCOS in the UK have differing health care experiences from those in the USA and therefore their experiences of the condition may have a different impact on quality of life. Schmid, Kirchengast, Vytiska-Binstorfer and Huber (2004) compared quality of life scores in the domains of infertility and menstrual cycle irregularities of Austrian women with Muslim women who had immigrated to Austria. They found that in these domains, the mean scores of the Muslim women were significantly higher than those of the Austrian women. Schmid et al. suggest that the differences may be cultural and due to the stronger social pressure for Muslim women to have children. This demonstrates how culture may have an impact on the quality of life of women with PCOS.

In the development of the PCOSQ, Cronin et al. (1998) selected items to be included in the scale after interviewing 10 women with PCOS and after a review of the literature. However, the questionnaire was developed and consequently published in 1998. At this time, there was no other qualitative literature, the first qualitative paper being published in 2002 (Kitzinger & Willmott), four years after Cronin et al. published their scale. Whilst the authors did conduct interviews with 10 of their patients, the items developed may not fully reflect the experience of women with PCOS and the impact the condition has on their quality of life. As the next qualitative paper exploring PCOS was not published until 2006 (Snyder, 2006), the same critique of lack of qualitative research informing the items could be levied at the later validations of the PCOSQ (Guyatt et al., 2004; Jones et al., 2004). Moreover, Cronin et al. (1998) focused on reviewing the existent medical literature, and thus may have not included all aspects of the psychological impact of PCOS on quality of life. Indeed, many of the findings of Chapter Three and Four, particularly the impact of PCOS on the psychological and social domains of quality of life experienced by women with PCOS, are not reflected in the items of the PCOSQ.

Another issue regarding the generalisability of the PCOSQ concerns Cronin et al.'s (1998) inclusion criteria when selecting women to interview, requiring patients to have symptoms of hyperandrogenism (elevation of testosterone, facial hirsutism and hair growth on the upper chest and back) and menstrual disturbance (such as oligomenorrhea and amenorrhea) only. This inclusion criterion excludes women with two phenotypes of PCOS as recognised by the Rotterdam 2003 consensus on diagnostic criteria (2004), the recommended diagnostic criteria for PCOS according to the NIH (2012). Specifically, women who present with polycystic ovaries combined with either oligo or anovulation, or indeed, clinical or biochemical signs of hyperandrogenism (Rotterdam, 2004) would have been excluded from the interviews and therefore, their perspectives would not have been taken into account when developing items for the scale. As such, the scale may be unrepresentative of women with PCOS in the UK on two fronts: differing experiences of health care systems (a privatised system versus a nationalised system) and differing symptom profiles.

Women with PCOS were also excluded from participating in the scale development process (from the interviews for item development to validation) if they presented with any other major illness that would influence their quality of life. However, as discussed in the previous

chapter, women with PCOS are at a high risk of developing other illnesses, often related to their PCOS, including depression (Dokras, Clifton, Futterweit & Wild, 2011), endometrial cancer (Balen, 2001), diabetes and heart disease (Harris & Carey, 2000). Patients were also excluded from this study if they were trying to conceive. As PCOS impacts on women's menstrual regularity and their ability to conceive this consequently excluded a large proportion of women with PCOS from the item development and validation stage of the scale development, who may have offered a different account of their lives with PCOS.

As a result of the item development stage, Cronin et al. (1998) had a final pool of 182 items which they 'intuitively categorized' (p. 1977) into eight domains. However, it is not clear how this categorisation was completed. The eight domains included: symptoms (47 items), emotions (43 items), social contacts and leisure activities (22 items), marital/partner sexual relationship (15 items), dating relationship (12 items), sexual functioning/sexuality (13 items), vocation/financial issues (15 items), and family/friends relationship (15 items). As such, the domains associated with the pool of items prior to item reduction were reflective of some domains of quality of life as detailed by the WHOQOL group (1994) including social relationships, physical health, environment and psychological health. However, during the item reduction stage of scale development, Cronin et al. (1998) detail that they specified that each domain on the scale should include four items; suggesting that the authors generated their own factor structure. Although the authors did use factor analysis within the item reduction phase, their aim was to place scale items in a domain and not to determine scale factors. Cronin et al. (1998) also detail the analyses they performed on their data; including a factor analysis on all items endorsed by 50% of the respondents. One hundred participants were included in the item reduction stage, however, research (Comrey, 1973; Field, 2013; Worthington & Whittaker, 2006) suggests that a sample size of 300 should be used for factor analysis. As such, of those items developed for the measure, Cronin et al. limited them first by pre-deciding the factor structure and then by only using items that were endorsed by half of the sample, which was arguably already limited due to the sample being unrepresentative of all phenotypes of PCOS. Malik-Aslam et al. (2010) similarly criticise this inclusion criteria for items and suggest that due to this cut off, many important issues that can impact on quality of life for women with PCOS may have been excluded.

Cronin et al. (1998) also fail to detail the number of participants included in the reduced item factor analysis after the initial items were removed, this further suggests that there was an

insufficient sample size to run a factor analysis. In addition, the factor analysis used by Cronin et al. (1998) is problematic; the authors used a principal components analysis (PCA) to analyse their data which assumes that there is no measurement error (Field, 2013). The authors also repeated the factor analysis using a varimax rotation suggesting that the items are independent and unrelated. However, for any data involving humans or exploring psychological constructs, in this case women with PCOS and quality of life, a varimax rotation should not be used (Field). Indeed, Field suggests that ‘there are strong grounds to believe that orthogonal rotations are complete nonsense for...data involving humans’ (p.644) due to the assumption that there is no relationship between the items.

As mentioned, in 2004 Guyatt et al. conducted a study to validate the PCOSQ, finding evidence of discriminative and longitudinal validity. However, the methods used by Guyatt et al. to validate the scale are also of concern. Primarily, patients involved in the validation of the PCOSQ were principally involved in a randomised controlled trial (RCT) exploring the effectiveness of Troglitazone (an anti-diabetic and anti-inflammatory drug) for the treatment of PCOS. Participants in this study were, therefore, already participating in research which may mean that they felt more supported than those experiencing routine care, or those outside of the health care system. The authors do recognise, however, that the PCOSQ may perform differently with patients outside of a clinical trial; as such, further validation of the PCOSQ with a non-clinical sample would still be required. In addition, as with the development sample, the validation sample was recruited from a US patient sample. Moreover, the only health related quality of life measure used within the validation was the PCOSQ, so the authors were unable to test the construct validity of the PCOSQ.

Guyatt et al. (2004) recognised several limitations with their validation of the PCOSQ, including the limited ability to make generalisations due to the lack of demographic information collected from participants (including symptom profile). In addition, the authors suggested that the scale may be unresponsive to change as it failed to find a difference in health-related quality of life in two of the five domains after a treatment intervention. Moreover, Guyatt et al. reported weak correlations between the PCOSQ and other measures (including measures of hair growth and menstrual cyclicity). As these traits are related this suggests that the PCOSQ has poor discriminative validity. Guyatt et al. also recognised that there is a need to test the construct validity of the PCOSQ with other health-related quality of life measures besides the PCOSQ.

An additional issue with the later validation (Guyatt et al., 2004) of the PCOSQ was the inclusion criteria used; as the authors failed to include women with PCOS who may have presented with polycystic ovaries, a recognised symptom of PCOS according to the 2003 Rotterdam criteria (2004). Patients were also excluded from this study if they were diagnosed with other disorders and if they were trying to conceive. Consequently, this excluded a large proportion of women with PCOS from the validation study. This suggests that the PCOSQ does not accurately represent quality of life for women with PCOS due to the restrictive exclusion criteria of the initial scale development and Guyatt et al.'s validation, which excluded women presenting with specific phenotypes of PCOS, women with PCOS who were trying to conceive and women with PCOS who experienced other disorders.

To confirm the structure of the PCOSQ as developed by Cronin et al. (1998), Guyatt et al. (2004) used the same limited development approach, a PCA and a varimax rotation. In addition, the factor analysis matrix presented in the Guyatt et al. (2004) paper, demonstrates that seven items load onto two factors or more, with one item loading on to three factors. Streiner and Norman (2008) advise that items which load on to two or more factors are likely to be 'tapping something other than what the developer intended' (p.96) and that these items should be discarded or rewritten. Guyatt et al. recognise several other issues with their validation of the PCOSQ. One example is the weak correlations between the PCOSQ and other measures (including measures of hair growth and menstrual cyclicality). Moreover, the authors suggest that the scale may be unresponsive to change. In addition, Guyatt et al. identify that there is a need to test the construct validity of the PCOSQ with other health-related quality of life measures. However, this was later partly completed by Jones et al. (2004) using the SF-36, a measure designed to survey health status (Ware & Sherbourne, 1992).

Overall, Jones et al. (2004) concluded that the PCOSQ was a reliable measure for health-related quality of life in women with PCOS with Cronbach's alphas ranging from 0.7-0.97 for all scales on the PCOSQ. The PCOSQ total score also correlated well with the SF-36 total score ($r=0.49$); though Jones et al. stated that the validity of the questionnaire needed to be improved by including a dimension of acne into the instrument. Similarly to Cronin et al. (1998) and Guyatt et al. (2004), Jones et al. excluded women with PCOS from their validation study if they experienced any other conditions. Moreover, participants were

recruited from a gynaecology clinic which the authors recognise may bias the participant sample towards women presenting with menstrual disturbances and infertility. As such, Jones et al. also failed to validate the PCOSQ with a representative sample of women with PCOS, including women with co-morbidities and those women who do not experience symptoms of menstrual disturbance or infertility.

Jones et al. (2004) did, however, attempt to gain reliability data in the form of a test-retest, asking participants to take part in a retest in order to look at the reliability of the scale over time. However, the retest occurred only three to six days after participants had completed the baseline measures. The time allowed in the retest was criticised by Malik-Aslam et al. (2010) who suggest that the time between the first and second administration of the PCOSQ was unusually short, questioning the length of the retest period, particularly as the recall period for the PCOSQ is over the last two weeks; meaning that the period of time considered by participants at baseline and at re-test overlapped. Although a three to six day retest period is adequate for scale development (Streiner & Norman, 2008) it could be considered inappropriate for a PCOS specific measure as women with this condition often experience irregular or absent menstrual periods (Elsenbruch et al., 2003); therefore a three to six day retest would not be considerate of participant's menstrual cycles.

Jones et al. (2004) also attempted to assess face validity of the PCOSQ by interviewing participants. One concern raised by participants was that the PCOSQ implied that PCOS was a short term condition. Although Jones et al. provide no further detail of this participant feedback, it may be that this is due to the length of the recall period (the last two weeks) that participants are asked to consider in relation to their PCOS when answering items in the PCOSQ. Similarly to Cronin et al. (1998) and Guyatt et al. (2004); Jones et al. also attempted to verify the factor structure of the PCOSQ using a PCA and varimax rotation. In addition, they performed these tests with a small sample size of only 82 participants. Coaley (2010) suggests that when using a small sample size in validity testing, there is a risk of a larger amount of error. Whilst the authors recognise the limitation of a small sample size, the issues of using a PCA, varimax rotation and a sample size of less than 300 for scale development, which have been discussed previously in this chapter, remain.

Further criticism of the PCOSQ comes from Malik-Aslam et al. (2010) who carried out a systematic review of nine published papers (including the three discussed in this introduction)

which aimed to identify PCOS specific quality of life measures and establish whether their development history and measurement properties supported their use in clinical trials. At this time there was only one PCOS specific quality of life measure, the PCOSQ. They state that there is a lack of evidence to attest to the suitability of the PCOSQ in terms of overall face and content validity. The convergent validity was found to be satisfactory, although this was only explored in two of the nine papers and responsiveness to change was only examined in one of the nine papers (Guyatt et al. 2004). Crucially, Malik-Aslam et al. claim that the PCOSQ is inadequate to assess the impact of PCOS on quality of life (Speight & McCann as cited in Malik-Aslam et al.), based on their own research. Indeed, they suggest that the PCOSQ would be better conceptualised as a measure of symptom bother and psychological well-being rather than a measure of quality of life.

The WHOQOL group (1994) propose that there are six domains of quality of life: physical health, psychological health, level of independence, social relationships, and environment and spirituality/religion/personal beliefs. Previous quality of life measures by the WHOQOL group have included psychological, physical, social, environmental and independence domains (WHOQOL Group, 1994; 2004). Fayers and Machin (2001), similarly, suggest that when developing a health status instrument there should be at least physical, emotional and social domains. The PCOSQ (Cronin et al. 1998) includes five subscales: emotions, body hair, infertility, weight and menstrual problems. Jones et al. also suggested in 2004 that an additional acne domain should be added to the questionnaire. However, even with the addition of an acne domain, the PCOSQ is overwhelmingly focused on the physical impact of the condition with four domains (body hair, infertility, weight and menstrual problems) on the impact of symptoms, falling within a largely physical domain of quality of life (Fayers & Machin, 2001; Testa & Simonson, 1996; WHOQOL Group, 1994).

The items in the PCOSQ (Cronin et al., 1998) subscale of emotions are less focused on physical symptoms than the other domains, mapping more clearly onto the emotional domain put forward by Fayers and Machin (2001), and arguably the domain of psychological health specified by the WHOQOL Group (1994). However, Guyatt et al. (2004) demonstrated that five of the seven items in the emotions domain also load onto at least one, if not two, other factors. This suggests that these items may represent a domain other than psychological health or emotions. In addition, as the items in this domain are vague, for example: 'depressed', 'tired easily', 'worried', 'moody', 'low self-esteem' and 'being self-conscious',

they may not fully represent the impact of PCOS on quality of life but may tap onto other factors outside of PCOS. For example, if a participant has recently been through a traumatic life event, they may also feel depressed, worried and moody. The PCOSQ, therefore, does not represent all the domains of quality of life, particularly the psychological, social and environmental domains, which may be impacted by the condition.

McGee (2004) suggested that when developing disease-specific measures, they should focus on the most important aspects of quality of life for the individuals with the specific health condition. In this case, PCOS-specific quality of life measures should represent the most important areas of quality of life for women with PCOS. The findings from Chapter Three and Four of this thesis also suggest that the PCOSQ may not fully represent all domains of quality of life that are important for women with PCOS including the impact of PCOS on social and psychological aspects of quality of life. Malik-Aslam et al. (2010) similarly suggest that a comprehensive measure of the impact of PCOS on quality of life needs to include all the relevant elements of life that can be affected by PCOS and that such a measure should be informed by interviews with women with PCOS (as in Chapter Four of this thesis).

It is clear that the PCOSQ is inadequate to measure quality of life for women in the UK due to the issues with its development, detailed in this chapter. Moreover, the PCOSQ overlooks areas of quality of life that are deemed important by women with PCOS in the UK, including psychological, social and environmental issues. As this thesis aims to further understanding and improve quality of life in women with PCOS in the UK, a new instrument should be developed to measure quality of life (DeVellis, 2012; Streiner & Norman, 2008). There is a need, therefore, for a PCOS specific quality of life measure which encompasses relevant areas of life that can be impacted by the condition as defined by women with PCOS.

5.1.1 Participant Feedback

As part of the interviews detailed in Chapter Four, participants were asked to provide feedback on the PCOSQ (Cronin et al., 1998). They were not given any further direction but were asked to provide any initial thoughts they may have on the scale. Overall participants commented positively on the scale items and stated that the items seemed like ‘quite valid statements’ or stated that they would agree to them all. However, several participants reported issues with the PCOSQ; for example, Debbie discussed how the scale did not discuss the impact of PCOS on their ‘jobs and relationships’. Holly discussed concerns over

the focus of questions on the PCOSQ towards physical symptoms rather than psychological or emotional symptoms: ‘a lot of the questions are about the physicality’s of PCOS like the hair and the weight. Erm for me it’s more mental’. Similarly, Julie referred to the lack of questions on infertility: ‘there’s a lot of, a lot of questions about weight and hair...there’s only a couple of questions about, about infertility or lack of fertility’. Compatible with these comments, Malik-Aslam et al. (2010) state that the PCOSQ mainly pertains to symptoms and that a quality of life measure for PCOS needs to consider the impact of the condition on all aspects of an individual’s life.

Another area of concern surrounded the recall period of the PCOSQ: Sharon questioned the recall period (the last two weeks) stating, ‘I mean ‘cause you pinpoint it down to two weeks, I wonder whether it would be different to be over a longer period. Two weeks is such a short space of time’. She goes on to recommend a ‘two month period’ which could encompass all the aspects of symptom management she experiences such as waxing excess hair growth and its regrowth. Emma had similar trepidations over the wording of the item ‘In relation to your last menstruation, how much were the following issues a problem for you’: she suggested that she had difficulty answering this item because she could not ‘remember’ her ‘last one’, referring to her menstrual cycle, in order to answer the question. This feedback suggests that the recall period, and the phrasing of questions, need to be improved in order to make the scale applicable for women with PCOS.

The need for a new disease-specific quality of life scale for use in clinical and research settings is evidenced by the limitations of the reliability and validity of the PCOSQ and by the criticisms from women with PCOS outlined above. This need is also supported by Malik-Aslam et al. (2010) who claim that there is a need for a PCOS specific quality of life measure that incorporates all the elements of life that can be impacted by PCOS. Consequently, this chapter details the development and testing of a psychometric quality of life scale, particularly for use with women with PCOS in the UK.

5.2 Methods and Results

5.2.1 Ethics

This study complied with The British Psychological Society’s ethical guidelines (BPS, 2009, 2010) and also complied with their guidelines for internet mediated research (2013). Ethical

approval was obtained from the Psychology Research Ethics Committee (Appendix K) at the University of Derby (06012-SWSW). All participants provided online consent to take part.

This scale development took place over four phases, using distinct participant samples: item generation (n=18), scale reduction and reliability (n=298), scale validity and re-test reliability (n=308) and further validation (n=108). All participants were required to read an information sheet (Appendix O) and give informed consent (Appendix P) before participating; and all participants were debriefed after participation (Appendix Q).

5.2.2 Phase I: Item generation

5.2.1.1 Participants and Procedure

Items were developed as a result of in-depth interviews with 10 women with PCOS (Chapter Four) and also through qualitative exploration of the impact of PCOS on quality of life (Chapter Three) that utilised photovoice methodology (see Williams, Sheffield & Knibb, 2014). All data was analysed using Thematic Analysis (Braun & Clarke, 2006): findings relating to identified themes were written as statements and formed the scale items (Kelly, Jenkinson & Ziebland, 2013). A literature review was also performed to help develop items for inclusion. The initial item pool reflected all the domains of quality of life reported by the WHOQOL group (1994), this included items pertaining to: physical health, psychological health, level of independence, social relationships and environment. There were also some items which discussed hope and optimism, reflecting the spirituality/religion/personal belief domain of quality of life (WHOQOL SRPB Group, 2006).

Once the initial item pool was developed this was reviewed by an expert panel (DeVellis, 2012). The expert panel comprised five persons with experience and knowledge of PCOS including consultant practitioners and academics with expertise in gynaecology, obstetrics, endocrinology, nutrition, long-term conditions and scale development. The panel was asked to provide feedback on the relevance of each item (high, moderate or low) and were afforded the opportunity to provide any additional comments. The panel were also asked to provide any feedback they may have on the structure of the scale and the language used. Overall, the scale feedback was positive, 'the questionnaire is detailed and relevant', resulting in all items being retained. As a result, the prototype Polycystic Ovary Syndrome Quality of Life (PCOSQOL) scale consisted of 62-items using a 7-point Likert scale ranging from 'Does Not

Apply' to 'Usually' (Appendix M). Participants were asked to respond to the statements by selecting the option that most reflected how they felt, they were advised there were no right or wrong answers and they were asked to consider the statements when reflecting on the past four weeks. Example items include: 'Felt under pressure to have a child', 'Felt like you weren't a real woman because of your PCOS' and 'Felt depressed about how PCOS has impacted your life'.

5.2.3 Phase II: Scale reduction and reliability

5.2.3.1 Statistical Analysis

Data analyses were conducted using SPSS version 22. First, the factor structure was tested using exploratory factor analysis. Then the internal consistency of the scale was assessed using Cronbach's alpha. Next, Spearman's correlations were conducted between scale scores to assess construct validity. Spearman's correlations were also performed to assess the discriminative validity of the PCOSQOL by comparing demographic data and condition characteristics. Confirmatory factor analysis was also used to test the structural validity of the scale.

5.2.3.2 Participants and Procedure

In order to reduce items in the prototype scale and assess the reliability, a large sample (n=298) of women with PCOS were recruited through the social networking website, Facebook (Appendix N). Groups included 'PCOS Cysterhood UK' and 'PCOS Awareness UK'. Inclusion criteria for the study were that the participants were: 18 years old and over, lived in the UK, had English as a first language and suffered from the symptoms of PCOS. Participants were not excluded if they suffered from other conditions in addition to their PCOS. Participants completed the prototype questionnaire anonymously. Two hundred and ninety eight participants completed the prototype PCOSQOL scale. Participants age ranged from 18 to 51 years old ($M_{age}=29.54$; $SD=6.26$).

5.2.3.3 Demographic Questions

All participants at each phase of the scale development process; scale reduction and reliability, scale validity and reliability and further validation, completed a questionnaire designed to gather demographic information from the participants. Questions were based on the findings of qualitative studies (Chapter Three and Four), and published literature. Information collected included the type of symptoms participants experienced, whether they

had received a diagnosis from a healthcare professional, length of diagnosis, medication and history of depression and anxiety, if any. Characteristics of participants can be found in Table 5.1.

5.2.3.4 Item Reduction

Item Analysis

Items in the prototype scale were analysed for frequency, means and correlations. Items with endorsement frequency rates (the proportion of people who give each response to alternative choices of an item) between 0.2 and 0.8 were retained (Streiner & Norman, 2008) which resulted in all items being retained. Analysis of item means too near to the extreme were removed resulting in the removal of five items with item means below 2 (1.78 to 1.92; DeVellis, 2012). Two of the removed items related to weight, 'Felt under pressure to lose weight' and 'Had negative thoughts about your weight'. One item related to the symptom of acne, 'Felt depressed because of the spots on your face' was also removed. All items significantly correlated with at least one other item; significant correlations ranged from 0.14 to 0.79.

An exploratory factor analysis was run on the data collected from participants at phase II (n=298). Principal axis factoring was employed using a direct oblimin rotation (Field, 2013). Initially, using eigenvalues above 1 as criteria for factor extraction, 12 factors were extracted. However, the scree plot (Figure 5.1) was ambiguous and showed inflexions that would justify retaining either 2 or 4 factors. Four factors had eigenvalues over 2; therefore, the analysis was rerun specifying the extraction of four factors. Coefficients below 0.45 were suppressed according to Comrey and Lee (1992). Of the 57 items, 35 had factor loadings of at least 0.45 and all of these items loaded onto one factor only. As a result 35 items were retained. After inspection of items loading onto each factor, subscales were labelled: Impact of PCOS, Infertility, Hirsutism and Mood. Results for the factor analysis can be seen in Table 5.2.

Table 5.1

Characteristics of participants who completed the scale at all stages (n=/%).

	Scale Reduction and Reliability n=298	Scale Validity & Re-test Reliability n=308	Further Validation n= 108
Marital Status: - Married - Civil Partnership - Divorced - Single - Living with Partner - Long-term Relationship - Engaged - Separated - Other	152(51.0%) 4(1.34%) 4(1.34%) 32(10.74%) 68(22.82%) 45(15.1%) 3(1.0%) 3(1.0%) 1(0.34%)	133(43.18%) 2(0.65%) 9(2.92%) 47(15.26%) 67(21.75%) 41(13.31%) 25(8.12%) 4(1.3%) 3(0.97%)	46(42.59%) 0 1(0.93%) 16(14.81%) 30(27.78%) 11(10.19%) 9(8.33%) 2(1.85%) 0
Children: - Had children - Were pregnant - Trying to conceive	107(35.91%) 12(4.03%) 144(48.32%)	86(27.92%) 17(5.52%) 125(40.58%)	48(44.44%) 4(3.7%) 38(35.19%)
Received a Clinical Diagnosis of: - PCOS - Depression - Anxiety	286(95.97%) 146(48.99%) 91(30.54%)	295(95.78%) 134(43.51%) 104(33.77%)	107(99.07%) 39(36.11%) 30(27.78%)
Symptoms Reported: - Infertility - Irregular Periods - Excess Weight - Skin Discolouration - Excess Hair - Acne - Alopecia - Skin Tags - Mood Swings	196(65.77%) 251(84.23%) 259(86.91%) 81(27.18%) 228(76.51%) 139(46.64%) 87(29.19%) 139(46.64%) 231(77.52%)	177(57.47%) 260(84.42%) 268(87.01%) 87(28.25%) 228(74.03%) 139(45.13%) 75(24.35%) 139(45.13%) 236(76.62%)	58(53.70%) 85(78.70%) 88(72.22%) 20(18.51%) 88(81.48%) 47(43.52%) 33(30.56%) 42(38.89%) 86(79.63%)

5.2.2.5 Reliability

Cronbach's alpha for the overall scale was excellent ($\alpha = .95$) as were the alphas for the four subscales: Impact of PCOS, Infertility, Hirsutism and Mood; $\alpha = .95$, $\alpha = .93$, $\alpha = .96$ & $\alpha = .85$, respectively. The closer Cronbach's alpha coefficient is to 1.0, the greater the internal consistency of the items in the scale (George & Mallery, 2003; Gliem & Gliem, 2003).

Nunnally (1978) also recommends that α should be at least .8, and should be at least .9 for a clinical instrument. Moreover, Ponterotto and Ruckdeschel (2007) state that for a scale with more than 11 items and a sample size of over 300, α would need to be .9 to be considered 'good'. Whilst some research may suggest that alpha's should not be over .9 as this indicates some redundancy in the scale (Streiner & Norman, 2008), the Cronbach's alphas for this scale are similar to those reported in previous scale development research (Burckhardt & Anderson, 2003; Hunt, Clark-Carter & Sheffield, 2011; Vaughan, Crooks, Locke, Veigas, Riches & Hilliam, 2010).

Table 5.2

Factor Analysis and Cronbach's alphas for the PCOSQOL and its subscales.

Overall Scale α = .948	Factor Loadings			
IMPACT OF PCOS (α = .95), Eigenvalue = 17.21, % of variance = 30.20	1	2	3	4
Felt like you weren't a real woman because of your PCOS	.818			
Felt abnormal because of your PCOS	.800			
Felt that it is unfair that you have PCOS	.727			
Felt angry that you have PCOS	.716			
Felt like you don't know what to do to control your PCOS	.705			
Been envious of women without PCOS	.678			
Felt embarrassed about the way you look	.666			
Felt like you don't know what to do to help yourself	.662			
Felt embarrassed about having PCOS	.653			
Felt like less of a woman because of having PCOS	.638			
Felt like your PCOS is in control of your life	.638			
Struggled to cope with your PCOS and your other condition(s)	.634			
Felt like you hated yourself	.613			
Felt depressed about how PCOS has impacted your life	.539			
Wanted to do something but haven't because of your PCOS	.503			
Wanted to take part in a social activity but haven't because of your PCOS	.499			
INFERTILITY (α = .95), Eigenvalue = 4.99, % of variance = 8.76				
Felt depressed over your struggle to have children		.940		
Felt depressed over difficulties conceiving a child		.917		
Felt depressed because of your infertility		.893		
Felt like a failure because of your trouble conceiving		.866		
Felt anxious about conceiving a child		.842		
Felt under pressure to have a child		.734		
Been scared that you may not have children		.723		
HIRSUTISM (α = .97), Eigenvalue = 4.11, % of variance = 7.22				
Felt embarrassed by your facial hair			.937	
Felt depressed because of your facial hair			.926	
Been worried about other people seeing your facial hair			.919	
Spent a lot of time and energy removing excess hair			.883	
Felt moody because of your excess hair			.876	
Felt depressed because of your hirsutism			.797	
MOOD (α = .89), Eigenvalue = 2.24, % of variance = 3.92				
Felt guilty for being overly aggressive towards a friend or family member				.715
Over reacted to a day to day occurrence because of your PCOS				.711
Had a short temper with your close friends and/or family				.664
Felt overwhelmed by your PCOS and depression				.595
Felt depressed				.482
Felt like crying for no reason				.459

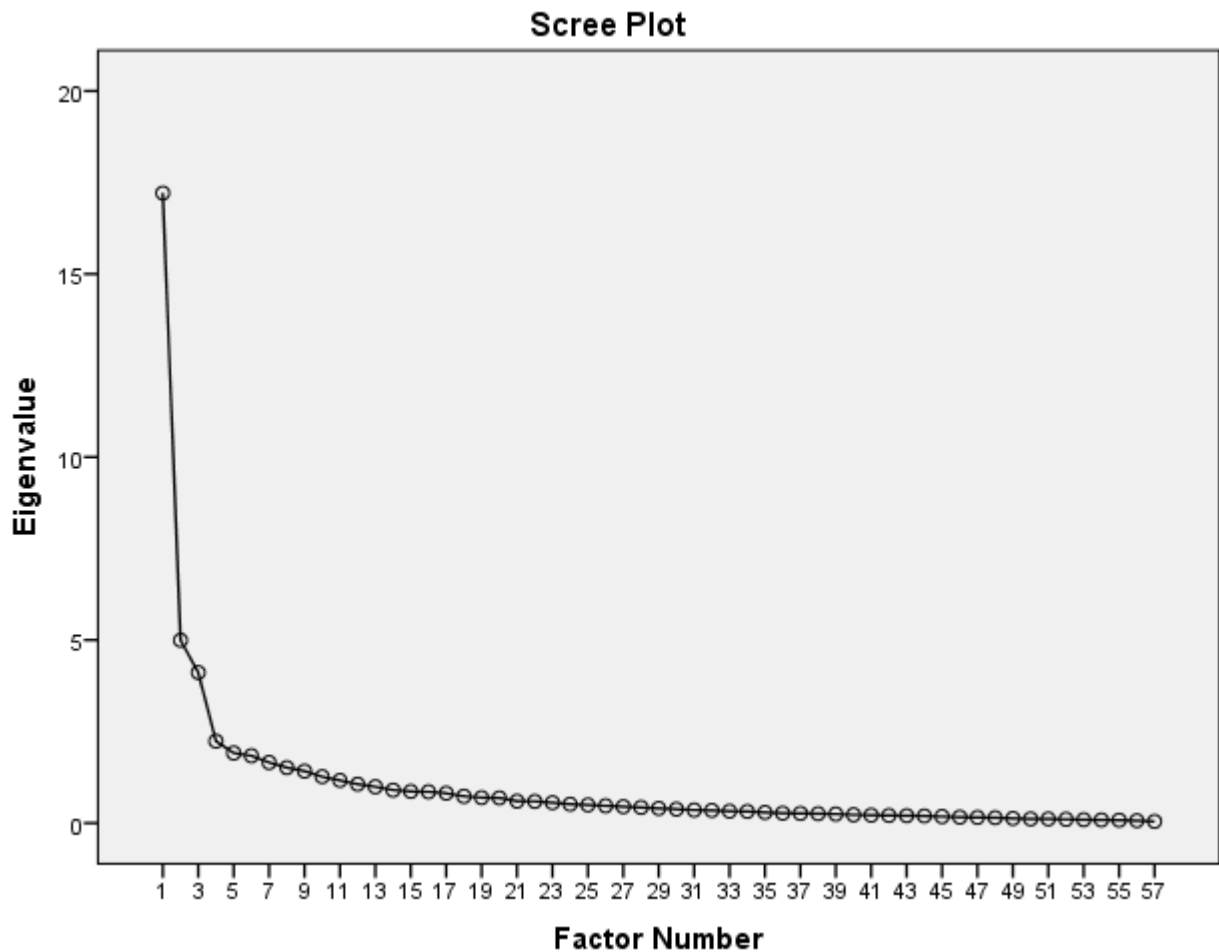


Figure 5.1 A scree plot as a result of a principal axis factor analysis (Phase II)

5.2.4 Phase III: Scale validity and re-test reliability

5.2.4.1 Participants and Procedure

To assess the construct and discriminative validity, and reliability of the reduced item PCOSQOL, a second large sample (n=308) of women with PCOS were recruited through the groups on the social networking website, Facebook. Inclusion criteria for the study were the same, in that the participants were: 18 years old and over, lived in the UK, had English as a first language and suffered from the symptoms of PCOS. Participants were not excluded if they suffered from other conditions in addition to their PCOS. Participants completed the PCOSQOL anonymously; however, participants were asked if they would like to take part in a test-retest to provide their consent and email address to this aspect of the study. The characteristics of the participants can be found in Table 5.1. Participants were also asked to

complete the Hospital Anxiety and Depression Scale (Zigmond & Snaith, 1983) alongside the reduced item PCOSQOL. Age ranged between 18 and 57 years old ($M_{age}= 29.88$; $SD=6.90$) and was normally distributed. Participants completed the questionnaires anonymously but were asked to provide their email address if they were happy to complete some of the questionnaire again three weeks later in order to check consistency of the PCOSQOL over time. A total of 90 participants completed the re-test of the PCOSQOL from this sample. Scores for the PCOSQOL in phase III were normally distributed as demonstrated by the Histograms (Figure 5.2).

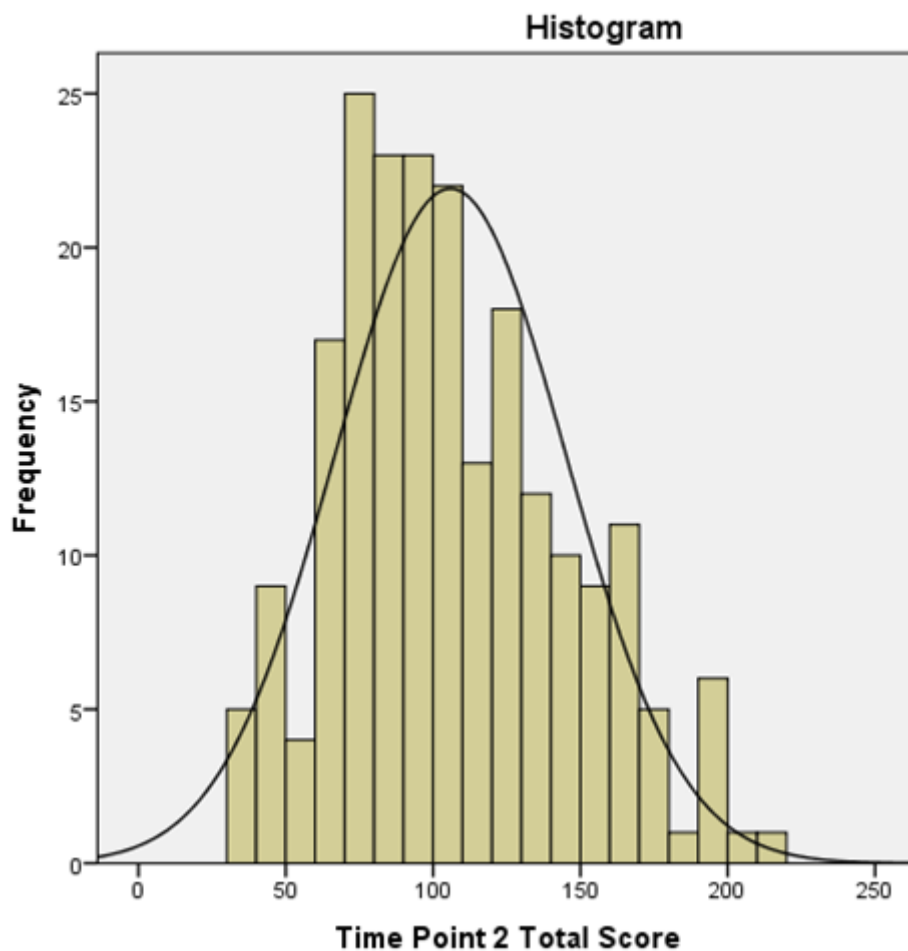


Figure 5.2 A histogram to demonstrate the distribution of data of the PCOSQOL scores at Phase III.

5.2.4.2 Cross-sectional Validation Measures

Hospital Anxiety and Depression Scale (HADS)

Three hundred and eight participants completed the Hospital Anxiety and Depression Scale (HADS; Zigmond & Snaith, 1983) and the PCOSQOL. HADS is a 14-item scale with seven items for each subscale (Depression and Anxiety) and each item is scored from zero to three. Items include 'I get sudden feelings of panic' and 'I feel cheerful'. The subscales for HADS have demonstrated good internal consistency, with Cronbach's alpha of 0.80 for the anxiety subscale and 0.76 for the depression subscale (Mykletun, Stordal & Dahl, 2001). The subscales for HADS also demonstrated internal consistency with this Phase III sample, with Cronbach's alpha of 0.72 for the anxiety subscale and 0.78 for the depression subscale. The results of the validity testing are detailed in Phase III.

5.2.4.3 Structural Validity

Confirmatory Factor Analysis

In order to test the factorial validity of the PCOSQOL scale, a confirmatory factor analysis was conducted in Analysis of Moment Structures (AMOS 17) to examine the four dimensional model identified in the exploratory factor analysis at phase II. The CFA revealed a large and highly significant chi squared; $\chi^2 (554) = 1925.720, p < .001$. However, this was expected as confirmatory factor analysis' Chi square is sensitive to large sample sizes (Hooper, Coughlan & Mullen, 2008; Kline, 1994).

Other goodness of fit measures were also taken including the comparative fit index (CFI) = .86 and the root mean square error of approximation (RMSEA) = .09. MacCallum, Browne and Sugawara (1996) suggest that RMSEA values in the range of 0.08 to 0.10 indicate a mediocre fit. However, Hu and Bentler (1999) suggest an RMSEA value close to .06 is needed before it can be concluded that there is a good fit between the model and the data. Indeed, Hooper et al. (2008) state that the RMSEA, in a well-fitting model, should be between 0 and 0.08. As such the RMSEA was greater than the cut off for a good fit, as was the CFI value of .86 since a value of 0.95 or above is considered a good fit (Hu & Bentler, 1999).

Saucier and Goldberg (1996), however, suggest that exploratory factor analysis provides a more rigorous replication test than confirmatory analysis and that an exploratory factor analysis may be preferred to a confirmatory analysis. DeVellis (2012) states that if data from

different samples of individuals on different occasions produce essentially identical factor analysis results using exploratory approaches, then the likelihood of those results being a 'quirk' is quite small. As such, a second exploratory factor analysis was run on the data collected from participants at phase III (n=308). Principal axis factoring was again employed using a direct oblimin rotation. Kaiser-Meyer-Olkin measure (KMO= .934) indicated that sampling adequacy was met. Factor analysis was conducted excluding for missing values pairwise. The scree plot supported a four factor structure (Figure 5.3). Coefficients below 0.45 were suppressed (Comrey & Lee, 1992). The factor analysis showed that all 35 items loaded onto the same factors as the exploratory factor analysis conducted in Phase II. Cronbach's alphas were checked again and found to be excellent for the overall scale ($\alpha = .948$) (George & Mallery, 2003), as well as for the four subscales; Impact of PCOS, Infertility, Hirsutism and Mood ($\alpha = .95$, $\alpha = .95$, $\alpha = .97$ and $\alpha = .89$).

5.2.4.4 Reliability and Consistency over Time

Ninety participants from Phase III (29%) completed a re-test of the PCOSQOL after three weeks. Correlation analyses were used to examine the relationship between the reduced item PCOSQOL and the test re-test data. Results indicated a strong, positive relationship between the total scores of the reduced item PCOSQOL and the test-retest data (missing data excluded pairwise), which was statistically significant ($r_{s[57]}=.902$, $p<.001$ BCa CI [.817, .948]). Mean scores were 105.67 ($SD=37.315$) for the PCOSQOL and 112.44 ($SD=38.41$) for the retest. This difference suggests that quality of life was improved for the participants at the re-test point. This was confirmed by a paired samples t-test which revealed a significant difference between scores of quality of life at Phase III and the re-test, $t(57)=-2.098$, $p<0.05$. This may be attributable to being part of the research. Cronbach's alpha for the re-test, for the overall scale was excellent ($\alpha = .949$) (George & Mallery, 2003), as well as for the four subscales; Impact of PCOS, Infertility, Hirsutism and Mood ($\alpha = .96$, $\alpha = .96$, $\alpha = .97$ and $\alpha = .89$).

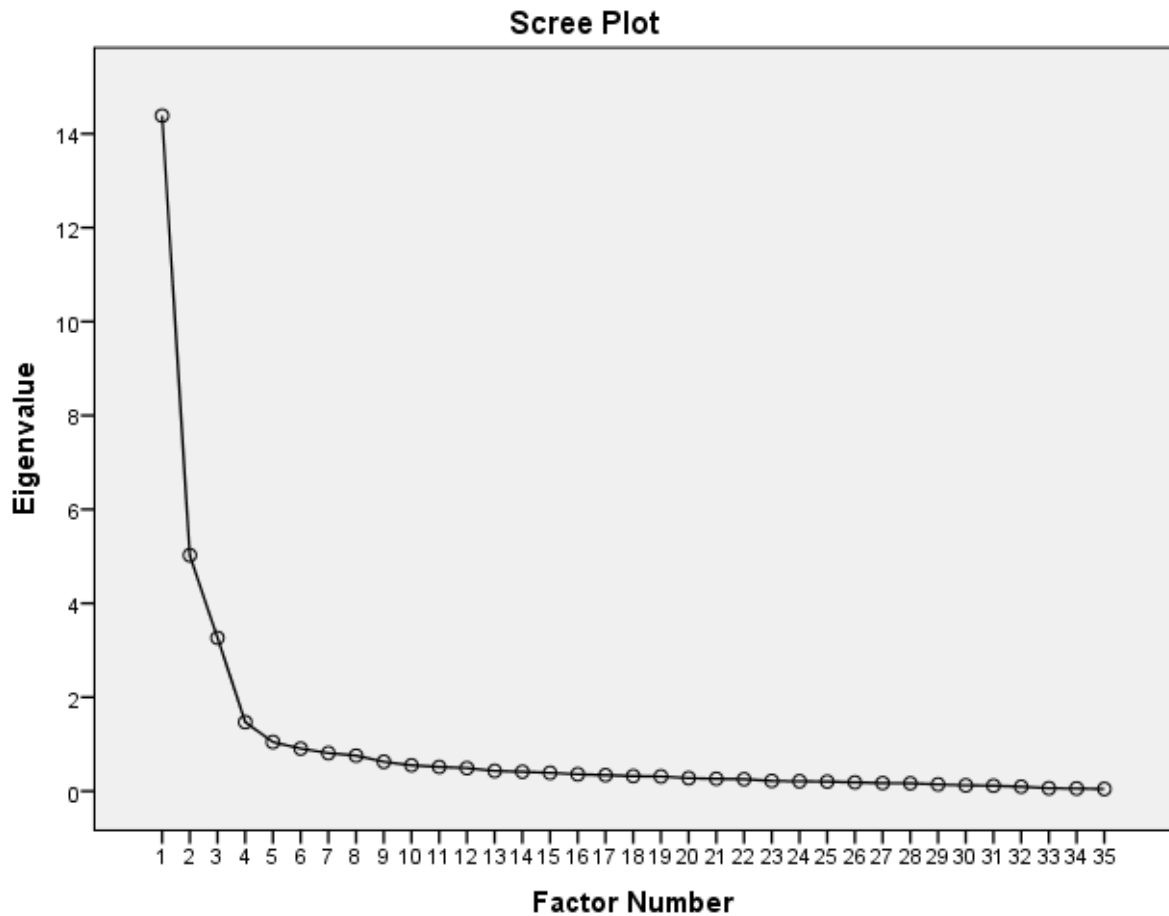


Figure 5.3 A scree plot as a result of principal axis factor analysis (Phase III).

5.2.5 Phase III: Further validation

Due to a loss of data during Phase III (occurring as a result of a software error), an additional 108 participants were recruited to complete the reduced item PCOSQOL and a further two cross-sectional validation measures including The WHOQOL-BREF and the PCOSQ (participant characteristics can be seen in Table 5.1). Participants were recruited through the same Facebook groups as detailed in previous phases, and using the same inclusion/exclusion criteria as detailed. Participants age ranged from 19 to 49 years old ($M_{age}=30.52$; $SD=6.51$).

5.2.5.1 Construct Validity

Cross-sectional Validation Measures

WHOQOL BREF

The WHOQOL-BREF (The WHOQOL Group, 1998) has 22-items and uses a 5-point Likert scale. It contains four subscales, including: Physical Health, Psychological, Environment and Social Relationships. Questions include issues regarding negative feelings, ability to perform daily activities, capacity to work and personal relationships. Cronbach's alpha for the scale has been found to be good for three domains; Physical ($\alpha=0.82$), Psychological ($\alpha=0.81$) and Environment ($\alpha=0.80$) but marginal ($\alpha=0.68$) for Social Relationships (Skevington, Lofty, O'Connell & the WHOQOL group, 2004). Cronbach's alpha for the participants in Phase III on the WHOQOL BREF domains were similar: Physical ($\alpha=0.86$), Psychological ($\alpha=0.85$) and Environment ($\alpha=0.78$), and Social Relationships ($\alpha=.70$).

POLYCYSTIC OVARY SYNDROME QUESTIONNAIRE

The PCOSQ (Cronin et al., 1998) is the only other disease-specific quality of life measure for women with PCOS to date. It has 26 items and uses a 7-point Likert scale. Questions focus on issues concerning growth of visible hair, infertility problems and feelings of depression. The PCOSQ has five domains: Emotions (eight items), Body Hair (five items), Weight (five items), Infertility problems (four items) and Menstrual problems (four items). Cronbach's alpha was above 0.7 when the PCOSQ was validated by Jones et al. (2004); however this must be treated with caution as the validation paper used different definitions of PCOS.

5.2.5.2 Cross-Sectional Correlation Analyses

Tests of normality revealed that the data were not normally distributed and therefore the non-parametric Spearman's correlation analysis was employed for all correlations including: the PCOSQOL and HADS, the PCOSQOL and the PCOSQ and the PCOSQOL and the WHOQOL-BREF. For correlation analyses all missing data was deleted pairwise to ensure consistency, and to retain as much data as possible.

PCOSQOL and HADS

Spearman's correlation was run to determine the relationship between the PCOSQOL, and its subscales, and the HADS subscales. Results are displayed in Table 5.3. This indicated that women with greater anxiety and depression had poorer PCOS quality of life.

Table 5.3

Spearman's correlation exploring the relationship between the PCOSQOL, its subscales and HADS.

	HADS Depression	HADS Anxiety
Impact of PCOS	-.615**	-.521**
Infertility	-.187**	-.240**
Hirsutism	-.357**	-.285**
Mood	-.563**	-.588**
PCOSQOL Total	-.532**	-.493**

* p<.05; ** p<.01

PCOSQOL and PCOSQ

Spearman's correlation analyses were used to examine the relationship between the PCOSQOL total score and the PCOSQ total score (Cronin et al., 1998). Results indicated a strong, positive relationship between the total scores of the PCOSQOL and the PCOSQ, which was statistically significant ($r_s[60]=.754, p<.001$).

PCOSQOL and WHOQOL-BREF

Spearman's correlation analyses were also used to examine the relationship between the subscales of the WHOQOL-BREF (Physical Health, Psychological Health, Social Relationships and Environment) and the PCOSQOL (Impact of PCOS, Infertility, Hirsutism and Mood), as demonstrated in Table 5.4 (n=87).

Correlation analyses revealed positive significant relationships between the PCOS subscales of Impact of PCOS and Mood and all the WHOQOL subscales. The PCOSQOL subscale, Hirsutism had positive weak to moderate correlations with three of the WHOQOL subscales: Psychological, Social Relationships and Environment domains. The PCOSQOL subscale Infertility demonstrated a significant weak, positive relationship with the WHOQOL subscales, Psychological and Environmental quality of life.

Table 5.4

Spearman's Correlations between the WHOQOL subscales and the PCOSQOL total scores and subscales (n=87).

* p<.05; ** p<.01

	Physical Health	Psychological	Social Relationships	Environment
Impact of PCOS	.422**	.646**	.342**	.514**
Infertility	.031	.255*	.028	.225*
Hirsutism	.144	.272**	.303**	.209*
Mood	.451**	.599**	.305**	.301**
PCOSQOL Total	.282**	.518**	.251*	.449**

5.2.5.3 Discriminative Validity of PCOSQOL

Independent t-tests revealed a significant difference in scores of quality of life between those participants who experience symptoms of infertility ($t(213)=1.220$, $p<0.001$), excess hair ($t(213)=5.099$, $p<.001$), excess weight ($t(213)=3.665$, $p<.001$), alopecia ($t(213)=2.598$, $p<.05$), skin tags ($t(213)=3.445$, $p<.001$), mood swings ($t(213)=5.531$, $p<.001$): or had received a clinical diagnosis of depression ($t(205)=-2.137$, $p<.05$) compared to women who had not. This suggests that for women with PCOS, experiencing these symptoms can have a negative impact on overall quality of life. There was also a significant difference in scores of quality of life for those women who were trying to conceive compared to those who were not ($t(193)=-6.482$, $p<.001$). Means and standard deviations can be found in Table 5.5.

Table 5.5

Mean (SD) quality of life scores for those women who did experience symptoms of PCOS, and have a diagnosis of depression, and those who did not.

	Quality of Life Scores (M,SD)	
	Did experience the characteristic	Did not experience the characteristic
Infertility	95.63, 36.80	120.99, 37.73
Excess Hair	98.34, 37.77	127.85, 34.77
Excess Weight	98.34, 37.77	127.85, 34.77
Alopecia	93.92, 29.58	109.80, 41.15
Skin Tags	96.36, 33.83	114.33, 41.65
Mood Swings	98.07, 35.62	130.38, 39.86
Diagnosis of Depression	99.37, 41.09	110.94, 36.68
Trying to Conceive	88.11, 30.57	120.56, 38.45

5.3 Discussion

This study aimed to develop a scale which will enable measurement of quality of life, as defined by women with PCOS in the UK, which is inclusive of all aspects of quality of life, which may be impacted by PCOS. In addition, this chapter details the reliability and validity testing of the disease-specific quality of life measure, the PCOSQOL, according to current scale development guidelines (DeVellis, 2012; Streiner & Norman, 2008).

The PCOSQOL was developed as a measure of quality of life for women with PCOS that was applicable for women with PCOS who also suffer from co-morbidities. Of the original 62 items in the prototype scale, 35 items were retained. Four subscales: Impact of PCOS, Infertility, Hirsutism and Mood, were generated using exploratory factor analysis; Cronbach's alpha for the overall scale and for each sub-scale was excellent and it also demonstrated good test re-test reliability and construct and discriminative validity.

Items for the PCOSQOL were developed from the qualitative findings of Chapter Three and Four of this thesis, expert opinion, and from a comprehensive literature review of both qualitative and quantitative data, as suggested by Malik-Aslam et al. (2010). The PCOSQOL was also developed (n=298) and validated (n=308) using a large sample of women with

PCOS, as recommended for factor analysis (Field, 2013). The PCOSQOL, therefore, was developed with a suitable sample size for factor analysis. In addition, the factor analysis utilised a direct oblimin rotation which assumes that the underlying psychological constructs are related (Field) and therefore overcomes the limitations levied at the PCOSQ and its later validations described earlier in this chapter (Cronin et al., 1998; Guyatt et al., 2004, Jones et al., 2004). The PCOSQOL also demonstrates sensitivity to co-morbidities, as demonstrated by the different PCOSQOL scores in women with and without diagnosis of depression, as well as the impact of symptoms on the participant (see Chapter Six for more detail).

The PCOSQOL includes items that were missing in the PCOSQ which reflected the social, psychological and environmental domains of quality of life. For example, the PCOSQOL included items such as; ‘Felt overwhelmed by your PCOS and depression’, ‘Wanted to do something but haven’t because of your PCOS’ and ‘Felt depressed about how PCOS has impacted your life’. The PCOSQOL also includes items which assess the impact of PCOS on feminine identity, the negative impact of PCOS on family and friends, feeling under pressure to have children and comparison to women without PCOS, all of which were not included in the PCOSQ. As such, the PCOSQOL includes items which are reflective of the psychological, social and environment domains which are important for a quality of life measure (Fayers & Machin, 2001; WHOQOL Group, 1994) and that were not included in the PCOSQ. However, items pertaining to the spirituality/religion/personal belief domain (WHOQOL Group, 1994) were not endorsed by participants in the item reduction phase and therefore were not included in the final PCOSQOL.

Whilst the PCOSQOL does not capture every aspect of quality of life as defined by the WHOQOL Group (1994), the items included are reflective of those aspects of quality of life which are deemed most important to women with PCOS in the UK. Thus the PCOSQOL focuses on issues of particular concern for women with PCOS (Fayers & Machin, 2007) and those areas perceived to be important to them (Osborne et al. 2014). The PCOSQOL, therefore, begins to address issues raised by Malik-Aslam et al. (2010) who suggest that a comprehensive measure of the impact of PCOS on quality of life needs to include all the relevant elements of life that can be affected by PCOS as detailed by women with PCOS through interviews.

The development of the PCOSQOL does have some limitations which need to be recognised. The scale was developed completely online, with recruitment via Facebook, email and data was collected using online questionnaire software. There were limitations to developing the scale online including lack of control over the participant population, specifically, whether they lived in the UK. The PCOSQOL was developed and tested for a UK sample; however, participants were not required to enter a postcode or state which region they lived in. Indeed, one participant (not based in the UK) did report that they had filled in the scale online, only to realise after completion that it was intended for a UK sample. As such, whilst this study cannot guarantee that the scale was developed with only a UK sample, the Facebook groups used for recruitment were intended for UK women with PCOS only. The scale development could have been improved, therefore, by asking participants to state where they were from and excluding those participants who were not based in the UK.

As participant recruitment for this study was completed via Facebook support groups, the participant sample may be unrepresentative of the general population as these women were already seeking support for their PCOS. There is also no way of verifying that the women who participated in this study had received a clinical diagnosis of PCOS, despite stating that they had. Moreover, it is also unclear what diagnostic criteria the women were diagnosed with, for example the Rotterdam criteria (2004) or the NIH (1991) criteria. Consequently, the PCOSQOL needs validating within a clinical population so that diagnosis of PCOS can be assured. Whilst this is a limitation of the development of the PCOSQOL, the demographic information provided by participants with regards to the symptoms they experienced suggests that participants represented all phenotypes of PCOS as detailed in the Rotterdam criteria (2004) including women who were diagnosed with polycystic ovaries. As such, the sample for this scale development is more inclusive than those used in the development and validation of the PCOSQ (Cronin et al., 1998; Guyatt et al., 2004; Jones et al., 2004) and, therefore, more representative of the different phenotypes of women with PCOS.

The 'Mood' subscale on the PCOSQOL contains six items, of these only two directly refer to PCOS. It is therefore possible that this subscale could measure effects of mood that are unrelated to PCOS; however, participants are advised to consider the questions in the PCOSQOL in relation to their PCOS. Future research should therefore explore how the

wording of these items may affect the measurement of quality of life for women with PCOS; this may lead to the alteration of items to directly refer to mood in relation to PCOS.

A further limitation of conducting this study was the lack of control over when participants completed the questionnaires in the test-retest aspect of the scale development. As participants were sent the link to complete the re-test measures via email it is possible that participants may not have completed the questionnaires on the day the email was sent. As such the test-retest period for this study, for some participants, may have been greater than the three weeks intended. This could have been overcome had participants been required to enter the date they completed the re-test on, so as to gather further information on the re-test period. However, as the retest period would have been extended rather than shortened, this suggests that the PCOSQOL may have demonstrated validity over a longer period of time than three weeks. Future validation studies of the PCOSQOL should, therefore, seek to complete further test-retests.

Completing the scale development online gave rise to online questionnaire software errors that resulted in lost data (two items from WHOQOL-BREF). As a consequence of this an additional 108 participants were recruited to complete the PCOSQOL and the WHOQOL-BREF. Similarly, a software error resulted in the loss of the demographic question concerning length of diagnosis throughout data collection. Therefore, it is suggested that if online software is used in data collection, investigators should pilot the software prior to data collection and check recording of data during data collection. Due to the loss of this data, future studies should aim to further validate the PCOSQOL in women with PCOS with differing lengths of diagnosis to ensure that it is applicable to those women who are newly diagnosed and as well as those who have been diagnosed for many years.

Analysis of the demographic data in this study revealed that women with PCOS are likely to have a diagnosis of depression and/or anxiety (see Chapter Six). However, this study did not explore the prevalence of any further co-morbid conditions that the participants may have experienced. Accordingly, future research should aim to validate the PCOSQOL for women with PCOS who suffer from a range of co-morbidities, inclusive of those discussed in Chapter Four of this thesis. In addition, the high prevalence of anxiety and depression in women with PCOS in this sample suggest the need for an intervention to improve quality of life and decrease levels of depression and anxiety. The sensitivity of the PCOSQOL to

change after an intervention will therefore be assessed in Chapter Seven of this thesis; so that further information with regards to the validity of the PCOSQOL as a measure of quality of life for women with PCOS in the UK can be gathered.

The PCOSQOL is the first UK disease-specific quality of life measure for women with PCOS which explores the impact of PCOS on all aspects of life, including psychological and social domains (Fayers & Machin, 2001; The WHOQOL Group, 1994) as recommended by Malik-Aslam et al. (2010). Moreover, the PCOSQOL improves on areas of the PCOSQ and its development, such as: an improved recall period, demonstrative construct and discriminative validity and development based on a representative sample of the population.

Streiner and Norman (2008) suggest that upon development of a new scale which measures a construct such as quality of life, then validation is not only necessary at the point of development but as an ongoing task. Streiner and Norman suggest, in accordance with Nunally (1994), that when validating a measure, the researcher is not simply validating the scale but how the scale is used, therefore a test may be valid for one purpose but not another. Furthermore, Nunally (1994) suggests that validation is ‘an unending process’ (p. 84), whereby psychological measures need to be consistently evaluated and re-evaluated. As such, in order to gain further information with regards to the validity and reliability of the PCOSQOL, the PCOSQOL shall be utilised within the next two chapters of this thesis (Chapter Six and Chapter Seven). Within Chapter Six the PCOSQOL shall be used to explore associations of quality of life with PCOS symptoms experienced by women with PCOS in the UK and within Chapter Seven it shall be used to measure the impact of an online positive psychology intervention on quality of life for women with, therefore, gaining further information about the validity of the PCOSQOL and how it can be used in different quality of life studies.

Chapter Six -Identifying and exploring the prevalence of PCOS symptoms and psychological co-morbid conditions and their association with quality of life.

The previous chapter and Chapter Two discuss in detail why the PCOSQ (Cronin et al., 1998) is not suitable to meet the overarching aims of this thesis (DeVellis, 2012). Consequently, Chapter Five detailed the development, and initial reliability and validity testing of a new disease-specific quality of life measure, the PCOSQOL. Studies which have not used the PCOSQ have utilised other generic quality of life measures such as the SF-36 (Ware & Sherbourne, 1992), which has been used by six studies that explore quality of life in women with PCOS (Açmaz et al., 2013; Ching, Burke & Stuckey, 2007; Coffey, Bano & Mason, 2006; Elsenbruch et al., 2003; Hahn et al., 2005; Jones et al., 2010), or the WHOQOL-BREF (Kumarapeli, Seneviratne & Wijeyaratne, 2011). As such, whilst the SF-36 and WHOQOL-BREF are considered reliable measures, they are not disease-specific and therefore provide an indication of overall health status or health-related quality of life and not quality of life as specifically associated with PCOS.

This thesis aims to further understanding, and improve quality of life in women with PCOS. Moreover, Chapter Four identified that two thirds of the sample of women with PCOS experienced depressive symptoms; as such this chapter also aims to investigate the prevalence of psychological co-morbid conditions in women with PCOS and their impact on quality of life. In addition, this chapter seeks to identify symptoms experience by women with PCOS and their prevalence. Once symptoms and psychological co-morbidities experienced by women with PCOS have been identified, and their prevalence assessed, this study will explore their association with quality of life in order to gain an understanding of the impact of PCOS on quality of life for women with PCOS in the UK.

6.1 Introduction

PCOS is characterised by many symptoms including: hirsutism, excess weight, acne, alopecia, and acanthosis nigricans (Lowenstein, 2006). However, to date there is only a small body of research which explores the associations of the symptoms experienced by women with PCOS and quality of life (Bazarganipour et al., 2013; Benetti-Pinto et al., 2014; Hahn et al., 2005; Khomami et al., 2015; Riddhi & Prajakta, 2015). The first study to explore the relationship of PCOS symptoms and quality of life was conducted by Hahn et al. in a 2005 study with participants from Germany. Hahn et al. reported that symptoms which had an

impact on an individual's outer appearance, including obesity and hirsutism, but not acne, were associated with lower quality of life scores (as measured by the SF-36). In addition, they found that BMI, hirsutism, acne, hyperandrogenism, menstrual irregularities and infertility were contributors to psychological problems in women with PCOS.

Jones et al. (2008) later explored the impact of PCOS symptoms on quality of life through a systematic review of the literature; this included studies which were methodological in focus, such as those related to the development and validation of the PCOSQ, and studies comparing quality of life in women with PCOS with other populations (including health conditions, cultures and normative population data). Overall, they found that the symptoms of acne, hirsutism, irregular menses, obesity and subfertility had a negative impact on quality of life.

Recently, a body of research from Iran has emerged which explores associations between clinical manifestations of PCOS and quality of life in Iranian women with PCOS.

Bazarganipour et al. (2013) found (using the MPCOSQ) that Iranian women with PCOS reported menstruation as their greatest concern and it had the most negative influence on quality of life. Symptoms of infertility were the second highest concern for the participants. However, Bazarganipour et al. note that these findings may have been impacted by the pressure on Iranian women to have children. In contrast, later research exploring the impact of symptoms on quality of life (using the PCOSQ) in Iranian women with PCOS found that hirsutism was reported as having the strongest impact on quality of life, followed by BMI, irregular menstruation and then infertility (Khomami et al., 2015). These studies demonstrate that for women in Iran, symptoms of infertility and irregular menstruation were of importance to both samples of women. However, there is some disagreement over the symptom of hirsutism and its impact on quality of life for women in Iran.

Research has also emerged from other countries: in an Indian study (Riddhi & Prajakta, 2015) the symptoms of body weight, followed by infertility, had the most impact on quality of life in women with PCOS (as measured by the PCOSQ). Similarly, in Brazilian women with PCOS (Benetti-Pinto, Ferreira, Antunes Jr. & Yela, 2014), body weight was found to be associated with worse quality of life (as measured by the WHOQOL-BREF) in comparison to a control group. The studies discussed here (Bazarganipour et al., 2013; Benetti-Pinto et al., 2014; Khomami et al., 2015; Riddhi & Prajakta, 2015), however, have gathered data from

women with PCOS in Asia and South America and as such, may not be applicable to the experiences of women with PCOS in the UK due to cultural differences and differences in healthcare systems. To date, there is little research which explores the impact and association of PCOS symptoms on quality of life for women in the UK, or the prevalence of those symptoms.

There is also limited research on the prevalence of some PCOS symptoms, particularly acanthosis nigricans (AN) which is a medical term for symptoms of skin discolouration and skin tags (NHS, 2013). Whilst previous research has demonstrated that there is a relationship between AN and insulin resistance (Barbato et al., 2012; Napolitano, Megna & Nofrecola, 2015) the relationship between AN and PCOS is unclear. Previous research explored the prevalence of AN in women with hyperandrogenism and found that in a sample of 300 women with clinically significant hyperandrogenism, 5% of women had AN (Flier, Eastman, Minaker, Matteson & Rowe, 1985). Later, Dunaif, Graf, Mandeli, Laumas and Dobrjansky (1987) found that AN was present in 29% of a sample of 62 hyperandrogenic women. However, a literature review revealed that, to date, no study has explored the prevalence of AN specifically in a population of women with PCOS. There is a need, therefore, to explore the prevalence of this symptom in women with PCOS in the UK.

Women with PCOS are likely to experience co-morbid conditions, as demonstrated in Chapter Four, particularly psychological conditions such as depression and anxiety (Cipkala-Gaffin, Talbott, Song, Bromberger & Wilson, 2012; Deeks, Gibson-Helm, Paul & Teede, 2011; McCook et al., 2005). In line with this, women with PCOS are more likely to experience the symptoms associated with anxiety and depression (Benson et al., 2009; Cinar et al., 2011; Deeks, Gibson-Helm & Teede, 2010; Dokras, Clifton, Futterweit & Wild, 2012). McCook, Bailey, Williams, Anand and Reame (2015) found that the menstrual problems experienced by women with PCOS, in a clinical sample of US women, were a strong predictor of psychological problems, as measured with the Brief Symptom Inventory (Derogatis, 1993). Furthermore, they found that symptoms of hirsutism and obesity also had a negative impact on psychological symptoms in women with PCOS in comparison to data from normative samples. However, there has yet to be research which explores the relationship of symptoms of PCOS and their association with psychological co-morbidities in women with PCOS in the UK.

In relation to anxiety specifically, previous research has suggested that women with PCOS are likely to experience an increased prevalence of generalised anxiety symptoms (Dokras et al., 2012). However, Dokras (2012) states that there is insufficient data examining the risk of other anxiety disorders such as social phobia, obsessive compulsive disorder and panic disorder. In addition, Dokras et al. (2011) suggest that only a few studies report other types of anxiety in addition to generalised anxiety disorder, detailing three studies which explore the prevalence of social phobia (Jedel et al., 2010; Månsson et al., 2008; Soyupek et al., 2008), two which explore obsessive compulsive disorder (Månsson et al.; Soyupek et al.) and two which explore panic disorders (Jedel et al.; Månsson et al.). Whilst, it is clear that women with PCOS are at an increased risk of experiencing anxiety disorders (Benson et al., 2009; Dokras et al., 2012) little is known about the relationship between PCOS symptoms and anxiety. Certainly, McCook et al. (2015) conclude that additional research is needed to explore the relationship of PCOS symptoms and psychological morbidity.

As mentioned, research suggests that there is a higher incidence of depression in women with PCOS (Månsson et al., 2008). Of concern, the findings of Chapter Four of this thesis revealed that some participants with PCOS who self-reported experiencing depressive symptoms, also discussed self-harm. To date, no study has explored the prevalence of self-harm in women with PCOS or its association with the condition and/or co-morbid psychological conditions. It is necessary, therefore, to further explore this phenomena, in relation to its prevalence and quality of life in a large sample of women with PCOS.

This study, therefore, aims: to investigate the prevalence of symptoms experienced by women with PCOS in the UK; to investigate the prevalence of psychological co-morbid conditions experienced by women with PCOS in the UK; and finally, to explore the association of PCOS symptoms and psychological co-morbid conditions with quality of life in women with PCOS in the UK.

6.2 Methods

6.2.1 Participants

Participants were recruited through a post to PCOS support groups held on Facebook.

Participants were included if they were aged 18 or over, lived in the UK and experienced the symptoms of PCOS. In total 714 participants completed the demographic questionnaires; 689 reported that they had received a diagnosis of PCOS from a health care professional.

Participants age ranged from 18 to 57 years old ($M_{age}=29.84$, $SD=6.53$). Further details regarding demographic information are included in Table 6.1.

Table 6.1

A table to show the demographics details of women with PCOS participants.

	Number and (%) of participants		Number and (%) of participants
Marital Status:		Received a Clinical Diagnosis of:	
- Married	331 (46.36)	- PCOS	688 (96.36)
- Civil Partnership	6 (0.84)	- Depression	319 (44.68)
- Divorced	14 (1.96)	- Anxiety	225 (31.51)
- Single	95 (13.31)		
- Living with Partner	165 (23.11)	Children:	
- Long-term Relationship	97 (13.56)	- Had children	241 (33.75)
- Engaged	37 (5.18)	- Were pregnant	33 (4.62)
- Separated	9 (1.26)	- Trying to conceive	307 (43.00)
- Other	4 (0.56)		
	0		

6.2.2 Procedure

The procedure for data collection was identical to that of Chapter Five. Participants were recruited through Facebook groups with the permission of the group administrator.

Participants were able to select a web link in the post where they could view the information sheet, consent form and fill in their demographic data. After completion in the study participants were debriefed and thanked for taking part.

6.2.3 Materials

Demographic data was collected online through questionnaire survey software LimeSurvey. Participants completed demographic data (Appendix U) and the PCOSQOL. Materials also included an information sheet, consent form and debrief.

6.2.4 Ethics

Ethical approval has been granted by the University of Derby Psychology Research Ethics Committee (PREC; Reference 086-13-SW). This study complies with the ethical guidelines of The British Psychological Society (BPS, 2009; 2010) and the BPS guidelines for internet mediated research (BPS, 2013).

6.2.5 Analytic Strategy

The variables were tested for normality using their histograms, the Kolmogorov-Smirnov and Shapiro-Wilk test. Data was analysed for frequency, and associations between categorical variables were analysed using Chi-Squared tests. Differences between variables were explored using independent t-tests. Due to the large sample size, missing data were excluded listwise. Data were analysed using frequency analyses; associations between categorical data were explored using Chi-Square tests. Shapiro Wilk tests revealed that data were not normally distributed and therefore Mann Whitney U tests were used to explore differences in scores of quality of life, and scores of the quality of life subscales between groups. A Monte Carlo method was used, as recommended for large samples (Field, 2013). Missing data were treated listwise. All tests were two-tailed.

6.3 Results

6.3.1 Participant Characteristics

Frequency analyses were conducted to explore the prevalence of symptoms experienced in the sample; findings are shown in Table 6.2. The symptom most experienced by participants was excess weight, followed by irregular periods, mood swings, hirsutism and infertility. Each of these symptoms was experienced by more than 50% of the sample.

Table 6.2

Frequency of symptoms experienced by women in the demographic analysis sample.

Symptom	N experienced	% of sample
Excess Weight	616	86.27
Irregular Periods	597	83.61
Mood Swings	554	77.59
Hirsutism	545	76.33
Infertility	431	60.36
Acne	326	45.66
Skin Tags	320	44.82
Alopecia	195	27.31
Skin Discolouration	188	26.33

Frequency analysis (detailed in Table 6.3) revealed that almost 45% of the population had received a clinical diagnosis of depression and almost a third of the sample had received a clinical diagnosis of anxiety. Moreover, almost a third of the sample had self-harmed at some point in their life.

Table 6.3

Frequency analysis of psychological co-morbidities, including: Depression, Anxiety, Self-Harm and Eating Disorders.

	N experienced	% of sample
Diagnosis of Depression	320	44.82
Diagnosis of Anxiety	225	31.52
History of Self Harm	230	32.21
- Self-harmed in the last three months	29	4.06
Diagnosis of an Eating Disorder	29	4.06
Diagnosis of Depression and Anxiety	178	24.93

Of those women who had a diagnosis of anxiety (n=162) 72% had generalised anxiety disorder (GAD), 35% had social anxiety disorder (SAD), 33% had panic disorder (PD), 14%

had obsessive compulsive disorder (OCD) and 16% had post-traumatic stress disorder (PTSD).

6.3.2 Associations

Chi-square tests were run to determine the associations between a history of self-harm, diagnosis of depression, diagnosis of anxiety and symptoms of PCOS. Significant findings are displayed in Table 6.4. Chi-square tests also revealed a significant association between a diagnosis of depression and a history of self-harm ($\chi^2=30.61$, $p<.001$).

Further Chi square tests were run to explore the associations between symptoms and types of anxiety disorder; results can be found in Table 6.5. Results demonstrated that all visible symptoms, except the symptom of acne, correlated with social anxiety disorder. The four symptoms of acne, alopecia, skin discolouration and skin tags identified above as correlating with a diagnosis of anxiety, also correlated with panic disorder.

Table 6.4

Results of Chi-Square analyses exploring associations between symptoms experienced and a diagnosis of depression, anxiety and a history of self-harm.

Symptom	Depression	Anxiety	Self-harm
Infertility	.226	.001	.010
Irregular Periods	2.46	2.28	.041
Hirsutism	2.82	.443	1.47
Acne	4.51*	4.21*	2.52
Weight	6.54*	3.15	2.05
Alopecia	4.66*	6.32*	.441
Skin Discolouration	4.60*	9.22*	1.26
Skin Tags	9.50*	13.06**	.056
Mood Swings	16.40**	4.27*	8.61*

*significant at the 0.05 level ** significant at the 0.01 level

A Mann Whitney U test revealed that women with PCOS had significantly different scores on quality of life if they experienced the symptom of infertility ($U=20952.50$, $p<.001$, $r=$), hirsutism ($U=14311.00$, $p<.001$, $r=$), acne ($U=30984.50$, $p<.05$, $r=$), excess weight

(U=9710.50, $p<.001$, $r=$), alopecia (22296.00, $p<.05$, $r=$), skin discolouration (U=22001.50, $p<.05$, $r=$), skin tags (U=28033.00, $p<.001$, $r=$) and mood swings (U=1419.00, $p<.001$, $r=$). Descriptive statistics can be found in Table 6.6.

A Mann Whitney U test found that women with PCOS who had also received a diagnosis of depression had significantly lower scores ($Mdn=83.00$) of quality of life than those women with PCOS without a diagnosis of depression ($Mdn=108.00$), $U=21651$, $p<.001$, $r=-0.28$. A Mann Whitney U test also found that women with PCOS who had a history of self-harm had significantly lower scores of quality of life ($Mdn=83.00$) than those women who did not have a history of self-harm ($Mdn=104.00$), $U=20080.50$, $p<.001$, $r=-0.22$.

Table 6.5

Results of a Chi Square test to explore associations between anxiety disorders and symptoms experienced.

Symptom	GAD	OCD	PTSD	SAD	PD
Infertility	.163	3.865*	.568	.511	.277
Irregular Periods	.139	.737	.351	.333	.032
Hirsutism	1.26	.368	.274	5.71*	.322
Acne	2.08	1.52	.000	2.37	6.30*
Weight	5.75*	.042	2.00	5.47*	1.46
Alopecia	5.56*	.011	2.99	5.48*	13.01**
Skin Discolouration	3.59	.418	1.20	9.75*	10.91**
Skin Tags	4.96*	.935	1.33	5.87*	4.76*
Mood Swings	5.87*	.887	.123	0.09*	12.26**

* Significant at the 0.05 level ** significant at the 0.01 level

Table 6.6

Median scores of quality of life (PCOSQOL) for those women who did and did not experience symptoms.

	Quality of Life Scores [Mdn]	
	Did experience the symptom	Did not experience the symptom
Infertility**	86.00	114.50
Irregular Periods	92.50	96.00
Hirsutism**	89.00	121.00
Acne*	93.00	98.50
Excess Weight**	92.50	131.00
Alopecia*	88.00	99.00
Skin Discolouration*	89.00	98.50
Skin Tags**	88.00	100.00
Mood Swings**	89.00	123.00

*Significant at the .05 level *significant at the .001 level

Mann Whitney U tests also found that women with PCOS who had a diagnosis of anxiety had significantly lower quality of life scores ($Mdn=88.00$) than those women without a diagnosis of anxiety ($Mdn=100.00$), $U=22563.50$, $p<.001$, $r=-0.14$. Moreover, scores of quality of life were significantly lower ($Mdn=88.00$) for women with a diagnosis of generalised anxiety disorder than those without ($Mdn=98.00$), $U=20959.50$, $p<.05$, $r=-0.12$. Scores were also significantly lower ($Mdn=79.00$) for women with a diagnosis of social anxiety disorder than those without ($Mdn=98.00$), $U=9324$, $p<.001$, $r=-0.18$ and scores were significantly lower ($Mdn=83.00$) for those women with panic disorder than those without ($Mdn=98.00$), $U=10371.50$, $p<.05$, $r=-0.12$.

Mann Whitney U tests were also run to explore differences between the four subscales of the PCOSQOL (Impact of PCOS, Infertility, Hirsutism and Mood) and a diagnosis of depression, anxiety and a history of self-harm. Results can be found in Table 6.7. Results indicated that the scores on the subscales Impact of PCOS, Hirsutism and Mood correlated with depression, anxiety and self-harm. However, the subscale of infertility only correlated with a history of self-harm.

Table 6.7

Results of Mann Whitney U tests exploring the differences between the PCOSQOL subscales and receiving a diagnosis of anxiety or depression and a history of self-harm.

PCOS Subscale	Depression	Anxiety	Self-Harm
Impact of PCOS	21313.50**	20737.50**	19757.00**
Infertility	29968.50	26880.00	24261.50*
Hirsutism	23896.50**	24305.00*	24010.00*
Mood	18246.50**	19500.00**	19423.00**

*U value is significant at the 0.05 level ** U Value is significant at the 0.01 level

Mann Whitney U tests were also used to explore the differences between the PCOSQOL subscales (Impact of PCOS, Infertility, Hirsutism and Mood) and the types of anxiety disorder (GAD, OCD, PTSD, SAD and PD). Results, displayed in Table 6.8, demonstrate that the subscale Hirsutism only correlated with Social Anxiety Disorder.

Table 6.8

Results of Mann Whitney U analyses exploring the differences between PCOSQOL subscales and type of anxiety disorder.

PCOS Subscale	GAD	OCD	PTSD	SAD	PD
Impact of PCOS	19292.50**	3859.50**	3758.50	8409.50**	8510.50**
Infertility	23478.00	5750.00	4714.50	12777.50	12862.5
Hirsutism	22436.00	5891.50	4641.00	9882.00**	11948.00
Mood	18261.00**	3626.50**	3066.50*	8207.50**	8513.00**

*U value is significant at the 0.05 level ** U value is significant at the 0.01 level

6.4 Discussion

This study aimed to identify the symptoms experienced by women with PCOS in the UK. It also aimed to identify co-morbid psychological conditions that women with PCOS in the UK may experience. Moreover, this study aimed to explore the association of symptoms experienced by women with PCOS, and any presenting co-morbid conditions, with quality of life. The symptom and co-morbidities of a large sample of women with PCOS (n=714) were

investigated in this study. The results highlighted that women with PCOS experience a range of symptoms including infertility, hirsutism, excess weight, alopecia, skin discolouration, skin tags and also mood swings. In addition, those women with PCOS who experienced the symptoms of infertility, hirsutism, weight, alopecia, skin discolouration, skin tags and mood swings had significantly lower scores of overall quality of life than those women with PCOS who did not experience the symptoms. The women in this study also reported clinical diagnoses of co-morbid psychological conditions of depression and anxiety. Furthermore, the results demonstrated that those women with PCOS who had previously received a diagnosis of depression or anxiety had lower quality of life than those women with PCOS without depression or anxiety.

Women who experienced the symptoms of infertility, hirsutism, weight, alopecia, skin discolouration, skin tags and mood swings had significantly lower scores of quality of life than those women who did not experience the symptoms. This suggests that as participants' symptoms decrease, quality of life increases. Previous research has detailed how hirsutism (Hahn et al., 2005) and excess weight (Barnard et al., 2007; Jones, Hall, Balen & Ledger, 2008) can impact quality of life. Similarly, Khomami et al. (2015), Riddhi and Prajakta (2015) and Benetti-Pinto et al. (2015) report that weight and hirsutism had the biggest impact on quality of life in women with PCOS, in their samples. Bazarganipour et al. (2013a) and Jones et al. (2008) also found that infertility had a negative impact on quality of life. However, to date, there is no other literature which explores the associations or relationships of skin discolouration and skin tags with quality of life.

As mentioned, infertility has been shown to negatively impact quality of life in women with PCOS (Elsenbruch et al., 2003; McCook et al., 2005). Interestingly, 60% of this sample experienced the symptom of infertility and of these participants almost a third had children. This suggests that women with PCOS classify themselves as experiencing the symptom of infertility even after childbirth, evidencing the continued negative impact of infertility on quality of life. Another explanation may be that of the participants that had children, 71 (32%) were trying to conceive for another child, suggesting that participants were still experiencing symptoms of infertility. This is defined as 'secondary infertility – where a person has had one or more pregnancies in the past, but is having difficulty conceiving again' as opposed to 'primary infertility – where someone has never conceived a child in the past has difficult conceiving' (NHS, 2014, para.7). Moreover, McCook et al. (2005) found that

women with PCOS who had never conceived, and women who had only experienced pregnancy losses, had significantly lower quality of life scores for the infertility subscale of the PCOSQ (Cronin et al., 1998). This study is limited, therefore, as it did not explore history of past fertility such as previous miscarriages which may have had an impact on participant's quality of life, and their perceptions of fertility. This suggests that women with PCOS are experiencing distinct phenotypes of infertility and as such, future research should aim to explore the experience of women with PCOS with both primary and secondary infertility. Accordingly, future studies exploring infertility in women with PCOS should also ensure that they specify which type of infertility their participants are experiencing, in order to gain further understanding of the two types of infertility in PCOS.

Almost 45% of participants experienced skin tags, as opposed to the lesser 26% who experienced skin discolouration. This suggests that women with PCOS may be more likely to experience the skin tags associated with AN than the skin discolouration. This is in contrast to Lowenstein (2006) who stated that skin tags, which are frequently observed with AN, had not been reported to be associated with PCOS. The symptom of skin tags was significantly associated with a diagnosis of depression. This further highlights the need for future research which aims to explore the prevalence of AN and the specific symptom profile (skin discolouration, skin tags) in women with PCOS and also explores the possible pathogenesis behind the association of skin tags and a diagnosis of depression. Moreover, the symptoms of acne, alopecia, skin discolouration and skin tags all had significant associations with a diagnosis of anxiety.

Previous research has suggested that the symptoms of hirsutism and obesity may be the trigger for social anxiety in women with PCOS (Månsson et al., 2008). This is supported by Chi square analyses that revealed that the symptoms of hirsutism and excess weight had significant associations with social anxiety disorder. Indeed, the women with social anxiety disorder had significantly lower scores on the Hirsutism subscale of the PCOSQOL, but there were no differences for any other type of anxiety. Research has also suggested that anxiety is elevated in women with PCOS with acne (Benson et al., 2009). However, in this study the symptoms of alopecia, skin discolouration and skin tags, but not acne, had significant associations with social anxiety disorder. Moreover, symptoms of alopecia, acne, skin discolouration and skin tags all had significant associations with panic disorder. As such future research should explore the prevalence of social anxiety disorder and panic disorder in

women with PCOS who suffer from anxiety. Moreover, the physical manifestations of PCOS that cannot be changed, such as skin tags, alopecia and skin discolouration, and their associations with social anxiety disorder and panic disorder should be investigated.

The analysis of demographic data revealed that of those women who had a diagnosis of anxiety (n=225), over 70% self-reported having Generalised Anxiety Disorder and over a third reported experiencing Social Anxiety Disorder and Panic Disorder. Consequently, this is the first study to explore the prevalence of each type of anxiety disorder but, it is limited by the omission of a comparator group from a population of women without PCOS. Future research should aim to explore the prevalence of anxiety disorders in women with PCOS, inclusive of Generalised Anxiety Disorder, Social Anxiety Disorder and Panic Disorder in comparison to a 'healthy' population of women. Moreover, as anxiety in this study was self-reported, future research should aim to explore the prevalence of clinically diagnosed anxiety disorders in women with PCOS.

Analysis revealed significant deflated quality of life scores for those women with a diagnosis of anxiety. Moreover, Mann Whitney U tests found significant differences in quality of life scores and generalised anxiety disorder, social anxiety disorder and panic disorder but not obsessive compulsive disorder or post-traumatic stress disorder suggesting that women with PCOS who also have an anxiety disorder (particularly generalised anxiety disorder, social anxiety disorder or panic disorder) may experience reduced quality of life. This finding supports the earlier analysis that revealed that symptoms of PCOS were significantly correlated with social anxiety disorder and panic disorder. This study is the first to highlight the relationship between the PCOS symptoms of alopecia, skin discolouration and skin tags and a diagnosis of anxiety. Interestingly, these symptoms are all concerned with aspects of body image that cannot be changed or managed as is possible with hirsutism (through waxing, shaving or plucking) and obesity (through diet and exercise). As such, future research should aim to explore the relationship between these PCOS symptoms and diagnoses of anxiety, particularly in relation to social anxiety disorder and panic disorder.

Infertility was significantly associated with a diagnosis of obsessive compulsive disorder but no other anxiety condition. Elsenbruch et al. (2003) similarly found that women with PCOS revealed significantly higher scores on the dimensions of obsessive-compulsive when measured with the SCL-90-R in comparison to healthy controls who scored within the normal

range. This was supported by Tan et al. (2008) who also found that women with PCOS had significantly increased scores on the domain of obsessive-compulsive on the SCL-90-R in comparison to population norms. It may be speculated that the obsessive behaviour present in women with PCOS is related to infertility, in particular, trying to conceive. Whilst not detailed in the chapter (Four), one participant (Julie) in the Skype™ study discussed how trying for a baby, including monitoring diet and exercise, was an ‘unhealthy obsession’ stating ‘it became an obsession...to an unhealthy level’.

In Britain, 88 per 1000 cases (9%) of people experienced co-occurring mixed anxiety and depressive disorders (Singleton, Bumpstead, O’Brien, Lee & Meltzer, 2000). However, in this sample 25% of the participants (178 out of 714) had been diagnosed with both depression and an anxiety disorder at some point in their lives. Indeed, almost half the participants (45%) in this sample reported receiving a diagnosis of depression from a health care professional. Moreover, when participants were asked ‘have you ever self-harmed?’ almost a third (32%) of the participants reported having previously self-harmed. Horrocks and House (2002) suggest that rates of self-harm in the UK are amongst the highest in Europe at 0.4% (400 per 100,000 cases per year). Interestingly, in this sample, rates of self-harm within the last three months were 10 times this amount (over 4% of the sample). Chi-square analyses revealed a significant association between a history of self-harm and a diagnosis of depression: 60.4% of women with PCOS who had a diagnosis of depression also had a history of self-harm, compared to 39.6% of women who had a history of self-harm without a diagnosis of depression.

Haw, Hawton, Houston and Townsend (2001) state that psychiatric disorders are common in deliberate self-harm patients; finding in a sample of 150 deliberate self-harm patients, that 138 (92%) had psychiatric disorders. Similarly, Horrocks and House (2002) suggest that up to three quarters of individuals suffer from depression at the time of self-harming. However, in this study only 136 (59%) of those participants with a history of self-harm had also received a diagnosis of depression. This suggests that many women with PCOS may be undiagnosed for depression; or, that women with PCOS have self-harmed (often referred to as self-injury) for other reasons, such as a coping mechanism (Laye-Gindhu & Schonert-Reichl, 2005). Consequently, further research is needed to explore the prevalence of self-harm in women with PCOS in comparison to ‘healthy’ women without PCOS, and the prevalence of psychiatric conditions in those women who do self-harm.

The prevalence of depression in women with PCOS has been well reported in the literature (Bhattacharya & Jha, 2009; Cinar et al., 2011; Rassi et al., 2010; Rasgon et al., 2003), however this is the first study to detail the high levels of a history of self-harm in the population. Klonsky and Olino (2008) distinguished between four different types of non-suicidal self-injurers (NSSI) including: experimental NSSI, mild NSSI, multiple functions/anxious group and an automatic functions/suicidal group. Similarly, Rodham, Hawton and Evans (2004) found that those students, who took overdoses, often had an intention to die, whereas those students who cut themselves reported this behaviour as self-punishment. This suggests that there are a variety of self-harm which can be undertaken for different reasons by different people.

Infertility subscale scores were significantly different for those women who had a history of self-harm, but not for those women with a diagnosis of depression. Interestingly, this further suggests that women with PCOS may experience self-harm independently to a psychiatric condition. Claes and Vandereycken (2007) state that self-harm could be considered as a way of coping with distress. Previous research has also suggested that individuals who deliberately harmed themselves were characterised by a propensity to use maladaptive, rather than adaptive, coping strategies (Mikolajczak, Petrides & Hurry, 2009). Indeed, the Affect-Regulation Model proposed by Suyemoto (1998) suggests that an individual's self-harm stems from a need to express anxiety or pain that cannot be expressed verbally or through other means; it is a method to gain control over emotions that would otherwise impact their sense of self. This is supported by Klonsky (2007) who suggest that individuals who self-harm may do so as they may be better able to cope with physical injuries, than emotional injuries. Certainly, as the research discussed here suggests (Klonsky, 2007; Klonsky & Olino, 2008; Rodham et al. 2004; Suyemoto, 1998), self-harm can have different meanings to different people, take different forms, and the intention when completing the self-harm behavior can be different for different people. As participants in this study were only asked if they had 'ever self-harmed', caution interpreting the findings regarding self-harm in this study is warranted. Future research, therefore, could explore how women with PCOS define self-harm, what it means to them, and what their intentions were when they completed the behavior.

Previous research has suggested that women with PCOS may experience disordered eating patterns (Jahanfar, Eden & Nguyent, 1995; Månsson et al., 2008; McCluskey, Evans, Lacey, Pearce & Jacobs, 1991). More recently, however, Larsson et al. (2015) found that there was no difference in current or previous symptoms of bulimia nervosa in women with PCOS, compared to controls. Indeed, in this sample less than 5% of participants reported receiving a diagnosis of an eating disorder, supporting the findings of Larsson et al. However, as participants were not asked if they experienced disordered eating behaviours, but only if they had a clinical diagnosis of an eating disorder, women with PCOS who did experience these behaviours may have been excluded from the analysis. Thus, there is still a lack of research exploring the prevalence of disordered eating in women with PCOS; therefore, future research should explore disordered eating in an undiagnosed sample of women with PCOS.

Previous studies have explored quality of life overall in women with PCOS previously (Barnard et al., 2007; Barzangipour et al., 2013b, 2014; Ching et al., 2007; Coffey et al., 2006; Elsenbruch et al., 2003; Jones et al., 2010; Kumarapeli et al., 2011). In addition, while there is also a growing body of research that explores the impact of individual PCOS symptoms on quality of life for women with PCOS across the globe (Açmaz et al., 2013; Bazarganipour et al., 2013a; Benetti-Pinto et al., 2015; Hahn et al., 2005; Khomami et al., 2015; McCook et al., 2005), this is the first study to explore associations of PCOS symptoms and quality of life in the UK. This study is limited however, as the participants in this study self-reported a diagnosis of PCOS and as such, their diagnosis is uncertain. Moreover, as the women in this study were recruited online from Facebook support groups, it could be argued that these women were already seeking support for their condition and may therefore not represent the larger population of women with PCOS in the UK. As such, future research should be carried out which explores the associations of symptoms of PCOS with quality of life in a clinical sample.

Through utilisation of the PCOSQOL, this study was able to provide further validation information of the scale as a disease-specific quality of life measure (Nunally, 1994; Streiner & Norman, 2008). In accordance with Streiner and Norman and Nunally, this study helped evaluate the use of the scale in studies which seek to explore the associations of quality of life with PCOS and its symptoms, thus providing further validation for the PCOSQOL. Use of the PCOSQOL in the next chapter (Chapter Seven) will also provide more information about

the efficacy of the PCOSQOL for use within an intervention which aims to improve quality of life in women with PCOS in the UK.

This study revealed the prevalence of symptoms, and psychological co-morbid conditions, in a large sample of women with PCOS in the UK. This study also reported the association of symptoms of PCOS with quality life, including infertility, hirsutism, weight, alopecia, skin discolouration, skin tags and mood swings being associated with lower quality of life than women who did not experience those symptoms. In addition, key areas for future research were identified: including an investigation of the prevalence and relationship of individual anxiety disorders in women with PCOS, and also an exploration of the prevalence of AN, in particular the symptom of skin tags, in women with PCOS in the UK. Overall, this study helped further understanding of the impact of PCOS, and its symptoms, on quality of life for women in the UK.

Chapter Seven -The impact of an online positive psychology intervention on quality of life for women with PCOS: A pilot study

The findings detailed in the previous chapters of this thesis demonstrate that women with PCOS in the UK experience a reduced quality of life, supporting previous research (Cinar et al., 2011; Coffey et al., 2006; Hahn et al., 2005). Moreover, the findings from Chapter Four and Chapter Six highlight that women with PCOS in the UK are likely to experience a psychological co-morbidity of depression and/or anxiety. In order to meet the latter half of the overall objective of this thesis, ‘to improve quality of life in women with PCOS’ it is necessary to identify, develop and test a pilot intervention which can increase quality of life in women with PCOS, who may also present with anxiety and depression. In addition, as detailed by Streiner and Norman (2008) and Nunally (1994) validation of a psychometric measure is an on-going task, and measures should be validated for different uses. As such, the PCOSQOL shall be used in this study in order to develop more evidence of the reliability and validity of the PCOSQOL as a disease-specific quality of life measure.

In 2013 the National Institute of Health (NIH) Office of Disease Prevention claimed that the cost to the US health care system to identify and manage PCOS was approximately \$4 billion annually (figures for the UK are unavailable). The panel also called for the establishment of programmes which aim to improve management of the syndrome for the women who have the condition. An intervention which can improve quality of life in women with PCOS, therefore, would not only help women with PCOS to manage their condition as recommended, but may also help to reduce costs to the health care system whilst improving the lives of women with PCOS. This chapter, therefore, aims to identify, develop and test the impact of an intervention for women with PCOS in the UK who may also experience symptoms of depression and anxiety.

7.1 Introduction

Research suggests that women with PCOS have higher levels of psychological distress including anxiety and depression than healthy women (Cinar et al., 2011; Deeks, Gibson-Helm & Teede, 2010; Dokras, Clifton, Futterweit & Wild, 2012; Månsson et al., 2008). Indeed, Lipton, Sherr, Elford, Rustin and Clayton (2006) found that in a sample of women

with PCOS over 74% had clinical levels of anxiety, over 30 % had clinical levels of depression and over 29% of women had clinical levels of both depression and anxiety. Additionally, Lipton et al. found that those women with higher levels of depression and anxiety reported poorer quality of life. Rassi et al. (2010) similarly reported that in a sample of 72 patients with PCOS, over half (57%) presented with at least one psychiatric diagnosis. Cipkala-Gaffin et al. (2012) similarly suggest that depressive symptoms are a significant psychological concern in women with PCOS. These studies demonstrate the extent that women with PCOS are at risk of developing and suffering from a mental health disorder, particularly anxiety and depression, and the impact this may have on their quality of life. This highlights the need for an intervention which may help women with PCOS to reduce their anxiety and depressive symptoms and improve their quality of life.

Interventions for women with PCOS to date have been largely based on lifestyle change and medical treatments, for example, Harris-Glocker et al. (2010) explored the effect of metformin combined with an oral contraceptive and lifestyle change on quality of life. Similarly, Hoeger et al. (2004) explored the impact lifestyle modification and metformin on ovulation and androgen concentrations in obese women with PCOS. Lass, Kleber, Winkel, Wunsch and Reinehr (2011) also explored the impact of lifestyle intervention, including nutrition education and exercise training, on biological symptoms such as menstrual irregularities and hyperandrogenemia in adolescents with PCOS. Moreover, Stamets et al. (2004) explored the impact of a dietary intervention on weight loss in obese women with PCOS. There have been few studies which explore the impact of interventions on psychological aspects of PCOS; indeed, Farrell and Antoni (2011) suggest that medical management of PCOS would benefit from the inclusion of psychological approaches.

One lifestyle intervention that has been found to have an impact on depression in women with PCOS was run by Galletly et al. (2007) who explored the psychological effects of a high protein, low carbohydrate diet in obese women with the condition. They found that that this diet was associated with a significant reduction in depression. Similarly, Thomson et al. (2010) explored the impact of lifestyle change on depression and quality of life. Participants were randomised into three groups: diet; diet and aerobic exercise; and diet and aerobic-resistance exercise. At the end of the 20-week intervention they found that all women had improvements in quality of life and in scores of depression. Consequently, it appears that lifestyle interventions can have a positive impact on quality of life and depression. Other

interventions have explored the impact of Cognitive Behavioural Therapy (CBT: Correa, Sperry & Darkes, 2015; Rofey et al., 2009). Rofey et al. (2009) explored the impact of CBT (over an eight week period) on depressive symptoms in adolescents with PCOS, and found that it reduced depressive symptoms and improved health-related quality of life. As such, lifestyle and CBT interventions have demonstrated some efficacy in reducing levels of depression and improving quality of life in women with PCOS, however, these interventions are resource and time heavy. It is clear therefore that there is a need for a psychological intervention which aims to improve quality of life, and symptoms of depression and anxiety, in women with PCOS which addresses these resource and time cost issues.

Psychological interventions have been shown to have a large impact on quality of life (Bennett, 2004). However, Bennett suggests that the challenge is to utilise psychological interventions in a wider healthcare setting than traditional interventions through the use of brief, cost-effective interventions that require minimal professional input. Moreover, Bennett proposes that interventions should be employed which require minimum input, but with the most benefit to a wide population. One group of psychological interventions gaining increasing focus, and demonstrating a growing evidence base of effectiveness, are positive psychology interventions (Donaldson, Dollwett & Rao, 2015). Specifically, positive psychology interventions have been shown to help improve depressive symptoms and well-being in a variety of populations (Bolier et al., 2013; Seligman, Steen, Park & Peterson, 2005; Sin & Lyumbomirsky, 2009).

Positive psychology has been described as the science of well-being and optimal functioning (Hefferon & Boniwell, 2011). It developed as an opposing force to the predominant focus of psychology on negative aspects of life, rather than the positive (Seligman, 2002; Seligman & Csikszentmihalyi, 2000). It is therefore concerned with optimal functioning (Gable & Haidt, 2005) and building positive traits (Seligman, 2002), rather than dysfunction as has arguably been the focus of psychology previously (Jørgensen & Natstad, 2005). Seligman called for psychology researchers to focus more on the positive aspects of human existence and less on pathology (Donaldson et al., 2015). Positive psychology, therefore, is aimed more towards prevention than treatment (Seligman, 2002). In line with this, Hefferon (2013) suggests that it is focused on enabling individuals from both clinical and non-clinical populations to be at their best. As such, positive psychology interventions may benefit all women with PCOS, both within a clinical and non-clinical setting.

Within the field of positive psychology, the Broaden-and-Build theory of positive emotions (Fredrickson, 2001) theorises ‘that experiences of positive emotions broaden people’s momentary thought-action repertoires, which in turn serves to build their enduring personal resources, ranging from physical and intellectual resources to social and psychological resources’ (p. 218). Positive emotions, such as love and gratitude, therefore broaden habitual ways of thinking and/or acting (Fredrickson). Fredrickson (2004) proposes that gratitude broadens people’s modes of thinking and habitual habits, by building their skills of showing appreciation. Fredrickson and Cohn (2010) suggest that people are willing to learn methods which enable them to generate positive emotions, including methods or positive psychology interventions built on gratitude. One type of positive psychology intervention based in gratitude are those where individual’s count their blessings, these interventions are normally reflective and self-focused (Fredrickson & Cohn, 2011). Through utilisation of positive psychology interventions, individuals are able to become more healthy and resilient. (Fredrickson, 2004).

Gratitude is the underlying concept for many positive psychology interventions (Hefferon, 2013) and the most widely used positive psychology interventions focus on gratitude (Park, 2014). Indeed, Lyubomirsky (2007) suggests that gratitude is causally linked to improvements in mental health, and that expressing gratitude during long-term illness can help an individual’s adjustment. Gratitude interventions have demonstrated an ability to decrease depression and increase well-being (Donaldson et al., 2015). Moreover, gratitude has been linked with improvements in health-related quality of life (Park, 2014). Gratitude interventions utilised by Seligman (2005), detailed below, included exercises such as writing down three good things, also known as counting blessings (Lyubomirsky, 2007) and making a gratitude visit (Seligman, 2005).

In 2005 Seligman et al. conducted a study exploring the impact of five online positive psychology interventions, activities included: a gratitude visit (write and deliver a letter of gratitude in person to someone who has been especially kind), listing three good things in life (list three things each day), you at your best (write about a time when you were at your best and reflect on personal strengths displayed), using signature strengths in a new way (use one of your top strengths in a new and different way) and identifying signature strengths (note five highest strengths and use them more often). For the signature strength exercises

participants were asked to complete a questionnaire to identify their character strengths, they were provided with feedback about their top five and then either asked to use one of the strengths in a new way every day for a week (using signature strengths in a new way) or to use any of the five more often during a week (identifying signature strengths). The control group were given an exercise called early memories whereby participants were asked to write about their early memories every night for one week. Participants were asked to complete measures at baseline and at five follow up points: immediate post-test, one week post-test, one month post-test, three months post-test and six months post-test. Seligman et al. (2005) found that two of the positive psychology exercises, using signature strengths in a new way and three good things (whereby participants were asked to write down three things that went well each day and their causes) both increased happiness and decreased depressive symptoms for six months. Participants in the three good things exercise were happier and less depressed than they had been at baseline and this effect was maintained at one month, three month and six months following the intervention. Although using signature strengths in a new way also showed long-term improvements for participants the immediate effects were less pronounced than for the participants in the three good things condition.

Later, Mitchell et al. (2009) used an online positive psychology intervention where participants were given three weeks to complete an intervention. Seligman et al. (2005) ran their positive psychology intervention for one week however later claimed that this was not enough time for participants in the three good things condition to gain enough skill. Manicavasagar et al. (2014) ran an online positive psychology intervention for adolescents (12 to 18 years old) for six consecutive weeks. Moreover, Sin and Lyubomirsky (2009) state that longer positive psychology interventions were also more like to produce greater gains in well-being and that the longer duration gives participants a chance to convert the positive psychology practices into habits. Online positive psychology interventions should therefore allow participants enough time to build the skills which will enable them to convert practice into habit.

As positive psychology interventions aim to cultivate positive feelings and behaviours (Sin & Lyubomirsky, 2009), they may be of benefit to all women with PCOS and not just those who are experiencing depressive symptoms. A non-invasive trial offering an online positive psychology intervention to women with PCOS may, therefore see improvements in quality of life and depressive symptoms in all women with PCOS. As such, a three good things

condition (Seligman, 2005) whereby participants write down three things that they are grateful for each day will be used as the intervention. This study aims to explore the benefits of an online positive psychology intervention for women with PCOS over a four week period, using quality of life as an endpoint and a two-week follow up, is proposed. This will be the first study to investigate whether an online intervention utilising positive psychology techniques can improve the quality of life of women with PCOS.

It is hypothesised that those participants completing the three goods things activity as part of the intervention group will experience a significant decrease in depression and anxiety scores when compared to the control group over the three study time points; baseline, post intervention and follow up. In addition, participants in the intervention group will experience a significant positive increase in quality of life scores overall and in particular within the subscales of Impact of PCOS and Mood, as these subscales contain items which pertain to depressive symptomology, when compared to participants in the control group over the three time points.

7.2 Methods

7.2.1 Online Positive Psychology Interventions

Positive psychology interventions are often delivered online (Mitchell, Vella-Brodrick & Klein, 2010; Seligman et al. 2005). The internet offers the potential to disseminate positive psychology interventions to a broad audience in an accessible and sustainable manner (Mitchell et al. 2009). The internet also offers easy access whilst maintaining anonymity, and it can be accessed at a person's own convenience, without the need for human interaction (Mitchell et al. 2010). Mitchell et al. concluded that well-being interventions could be effectively delivered via the internet; this is beneficial for women with PCOS as studies suggest that they can be socially isolated (Percy et al., 2009; Washington, 2005).

7.2.2 Design

A 2x3 independent measures design was employed to explore the impact of an online positive psychology intervention on quality of life, depression and anxiety. Measures were captured between groups (control and intervention group) at three time points (pre-intervention, post-intervention and follow up).

7.2.3 Participants

Participants who experienced the symptoms of PCOS were recruited through Facebook groups intended to be used by women with PCOS. Inclusion criteria for the study were that participants were: aged 18 and over, lived in the UK, had access to the internet and suffered from the symptoms of PCOS. Exclusion criteria included participants who self-reported a mental incapacity who were unable to give informed consent and participants who were unable to understand verbal and written information in English. The participants' ages ranged from 21 to 49 years old with a mean age of 30.2 (SD=6.18) years. Participant figures at each stage of the intervention can be seen in Figure 7.1. Of the 76 participants, most classified themselves as White (n=57) and/or British (n=54), and the majority of participants were married (n=37). Four of the participants were currently pregnant, but all reported being more than 10 weeks away from their due date at the time of filling in their demographic questionnaire, 29 participants were trying to conceive.

The participants experienced a variety of symptoms including: infertility (n=44), hirsutism (n=58), excess weight (n=60), mood swings (n=58), insulin resistance (n=33), skin tags (n=32), acne (n=32) and male patterned hair loss (n=21). Of the 76 participants who completed demographic data and were randomised, 75 self-reported receiving an official diagnosis of PCOS. Thirty eight had received a clinical diagnosis of depression and 19 had received a clinical diagnosis of anxiety; 14 participants had received a clinical diagnosis of both. Moreover, 17 participants had a history of self-harm and seven participants had a diagnosis of an eating disorder.

7.2.4 Materials

The primary study endpoint for this research was quality of life. Quality of life was measured using the PCOSQOL Scale (developed and validated in Chapters Five and Six) and the Hospital Anxiety and Depression Scale (HADS; Zigmond & Snaith, 1983). Psychometric properties for each of these measures can be found in Chapter Five. Materials also included an information sheet, consent form, demographic questions, online intervention instructions and debrief (Appendix V to AA). Participants were also sent evaluation questions which included Likert scale and open text box questions, such as; 'please tell us about your experience on the positive psychology intervention'.

7.2.5 Procedure

Participants were recruited through a post on Facebook. The post detailed the inclusion criteria and information regarding withdrawal and confidentiality of data. Also included was a link to the information sheet and demographic questionnaires. Upon clicking this link participants were directed to a website where they could read the information sheet, fill in the consent form and complete their demographic information. Once complete, participants were blindly randomised by a member of the research team (Dr. H Sowter) using randomisation software from Randomization.com as reviewed by Saghaei (2011) and Suresh (2011). This software is also listed on the 'directory of randomisation software and services' website (Bland, 2014). All participants in the control group were offered the intervention after the follow-up period. Randomisation software is available here:

http://www.jerrydallal.com/random/random_block_size_r.htm.

Participants in the intervention group were directed to Qualtrics; an online survey website (via email) and asked to complete the baseline measures. Once they had completed these measures, participants were emailed and directed to Qualtrics to complete their positive psychology exercise, three good things, for 28 days by typing them in the boxes provided. Participants were sent daily reminders to the email address they provided. Participants in the control group were not asked to complete any exercise for the duration of the study nor were they contacted during the 28 days. Intervention participants were asked to complete their three good things exercise daily towards the end of each day. If participants were unable to get online for whatever reason they were advised to write their three good things by any other method (on paper, on their mobile phone) and then to send these to the researcher at the next opportunity, or to follow the web link for that day. Participants were informed in the study instructions that if they could not think of three good things to write, to write as many as they could think of.

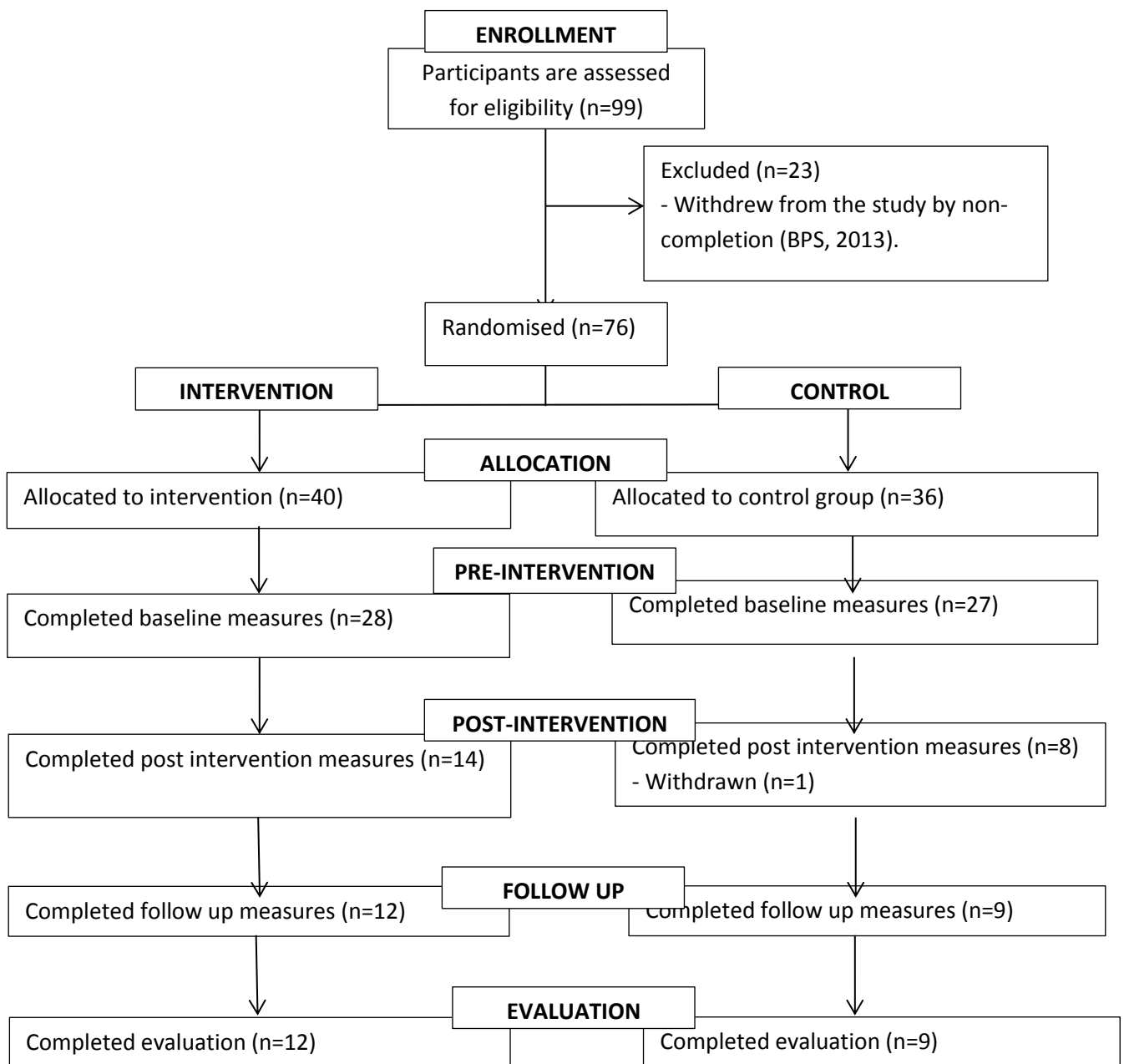


Figure 7.1 A CONSORT diagram to show progress through the five stages of the intervention: Recruitment, randomisation, baseline measures, post intervention measures and follow up measures.

Participants in both arms of the study were asked to complete the PCOSQOL scale and the Hospital Anxiety and Depression Scale (Zigmond & Snaith, 1983) questionnaires at baseline, on completion of the intervention (or four weeks after completing baseline measures for the control arm) and at a two week follow up. Participants were directed to an online website to complete these; all questionnaires were held online. All questionnaire data was retained with

a unique identifying code: follow up emails and reminders were sent to the participants' email addresses.

Once data collection for the study was complete; participants were sent an email containing a link to evaluation questions to assess the feasibility and impact of the online positive psychology intervention. All participants who completed the baseline data (n=55) were asked to complete an anonymous, brief evaluation questionnaire on; how much they enjoyed the intervention, ease of use, their experience of the intervention and an opportunity to give any other comments.. Questions included; 'How easy did you find it to complete the intervention...'" whereby participants were asked to rate on a scale of one to seven where one is 'Very Difficult' and seven is 'Very Easy' how easy they found the intervention to complete: and the open question, "Please tell us about your experience on the positive psychology intervention...".

7.2.6 Ethics

Ethical approval was granted by the University of Derby Psychology Research Ethics Committee (PREC; Reference 086-13-SW). This study complies with the ethical guidelines of The British Psychological Society (BPS, 2009) and the BPS guidelines for internet mediated research (BPS, 2013).

7.2.7 Analytic Strategy

Data was analysed using SPSS version 22. The continuous variables were tested for normality using their histograms, the Kolmogorov-Smirnov and Shapiro-Wilk test. To explore the differences in scores of quality of life, anxiety and depression between those participants in the intervention and control group, at pre and post intervention and follow up; a 2x3 mixed model ANOVA was employed. To explore the differences between scores on the subscales on the PCOSQOL (Impact of PCOS, Infertility, Hirsutism and Mood); a 2x3 mixed model ANOVA was also employed. All tests were two-tailed.

7.3 Results

In total, 55 participants completed baseline measures. Of these, 14 participants completed measures at all time points (pre-intervention, post intervention and follow-up). Chi-square analysis revealed that there was a significant difference between those participants who completed baseline measures (or more) after randomization and those who did not, and the

symptom of mood swings ($\chi^2(1)=4.099$, $N=76$, $p<0.05$). Of those participants who did not take part in the study after randomisation, 91.3% experienced the symptom of mood swings compared to 69.8% who took part in the study. There were no other significant differences between those participants who took part after randomisation and those who did not.

7.3.1 Quality of Life

Mauchly's Test of Sphericity indicated that the assumption of sphericity had been violated, $X^2(2)=8.107$, $p<.05$, and therefore, a Greenhouse-Geisser correction was used. A mixed design ANOVA found a significant main effect of the time point that participants completed the quality of life measures (pre, post and follow up), $F(1.286,14.144)=5.438$, $p<.05$, $r=0.53$, seen in Figure 7.2. Contrasts revealed that quality of life scores were significantly higher at follow-up than at baseline, $F(1,11)=6.971$, $p<.05$, $r=0.6$. However, there was no significant effect for quality of life scores post intervention and at follow-up, $F(1,11)=.098$, $p=.76$, $r=0.09$. There was no significant effect of group, indicating that quality of life scores from the intervention and control group were similar, $F(1,11)=.159$, $p=.70$, $r=0.11$. There was also no significant interaction effect between the time point the quality of life measures were completed and the group (control or intervention) $F(1.286, 14.144)=.606$, $p=.49$, $r=0.20$.

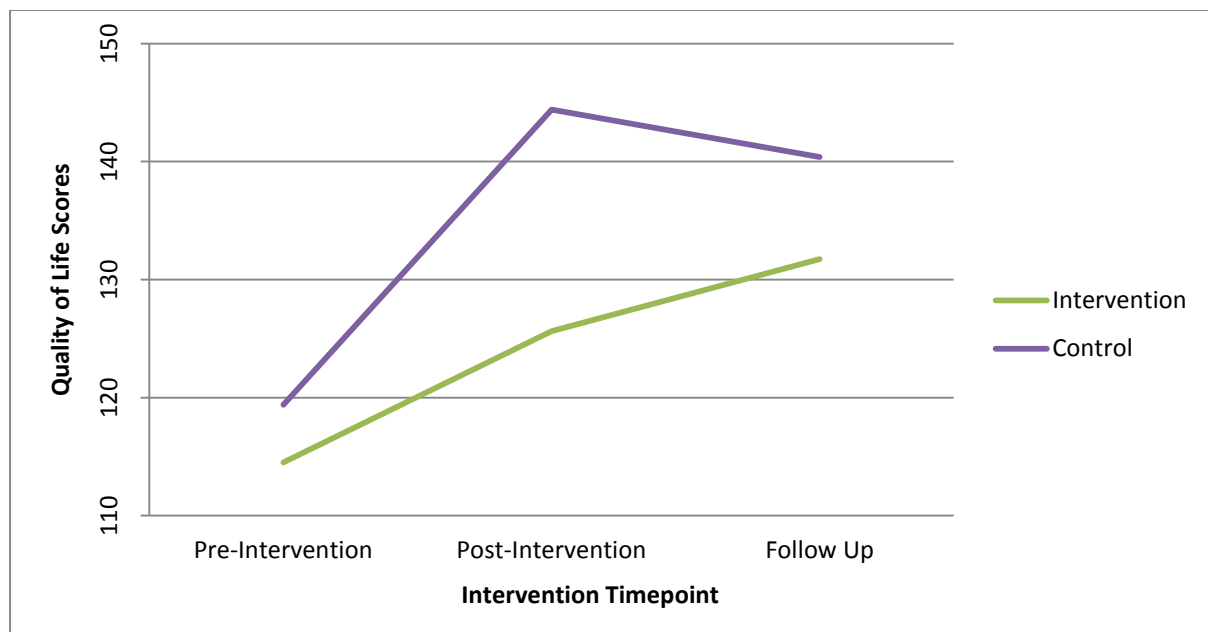


Figure 7.2 PCOSQOL mean scores of quality of life across all three time points.

Descriptive statistics shown in Table 7.1 suggest that being part of a study had a positive impact on participants' quality of life, regardless of the condition. However, this impact was not maintained at follow-up for participants in the control group.

For the Hirsutism subscale, a 2x3 mixed design ANOVA did not find a significant main effect of the time point that participants completed the PCOSQOL subscale of 'Hirsutism' (pre, post and follow up), $F(2,24)=1.542$, $p=.23$, $r=0.25$. There was also no significant interaction effect between the time the quality of life measures were completed and the group (control or intervention) $F(2,24)=1.667$, $p=.21$, $r=0.25$. There was no significant effect of group, indicating that Hirsutism scores from the intervention and control group were similar, $F(1,12)=3.553$, $p=.08$, $r=0.48$.

Table 7.1

Means and Standard deviations for all measures at all-time points for the Control (C) and Intervention (I) conditions.

		Baseline [M, SD]	Post Intervention [M, SD]	Follow Up [M, SD]
Quality of Life	C	119.40, 51.81	144.40, 49.10	140.40, 49.07
	I	114.50, 33.43	125.63, 54.46	131.75, 55.12
Impact of PCOS	C	49.80, 27.63	62.60, 27.74	59.00, 28.11
	I	49.63, 18.28	55.00, 27.16	57.50, 28.24
Infertility	C	19.00, 15.07	24.40, 12.60	24.20, 13.31
	I	24.75, 14.45	26.88, 13.16	28.38, 13.52
Hirsutism	C	31.80, 8.87	33.20, 6.14	35.20, 6.69
	I	21.22, 13.37	19.89, 14.42	21.00, 14.48
Mood	C	24.40, 13.65	24.20, 13.85	22.00, 13.58
	I	18.78, 7.40	20.89, 8.82	21.22, 9.54
Depression	C	5.20, 4.82	5.80, 4.09	4.00, 4.30
	I	6.38, 5.66	6.13, 4.42	5.38, 3.54
Anxiety	C	9.80, 8.14	9.20, 5.92	8.20, 7.92
	I	10.25, 6.14	9.25, 5.92	9.75, 6.07

C = Control Group, I= Intervention Group

For the Impact of PCOS subscale, a 2x3 mixed design ANOVA found a significant main effect of the time point that participants completed the PCOSQOL subscale of ‘Impact of PCOS’ (pre, post and follow up), $F(2,22)=4.642$, $p<.05$, $r=0.42$. Contrasts revealed that there was a significant effect for Impact of PCOS scores at pre intervention and follow up, $F(1,11)=.046$, $p<.05$, $r=0.06$ (see Figure 7.3). However, Impact of PCOS scores were not significantly higher at follow-up than at the end of study measures, $F(1,11)=.066$, $p=.80$, $r=0.08$. There was also no significant interaction effect between the time point the quality of life measures were completed and the group (control or intervention) $F(2,22)=.701$ $p=.51$, $r=0.18$. There was no significant effect of group, indicating that Impact of PCOS scores from the intervention and control group were similar, $F(1,11)=.047$, $p=.83$, $r=0.07$.

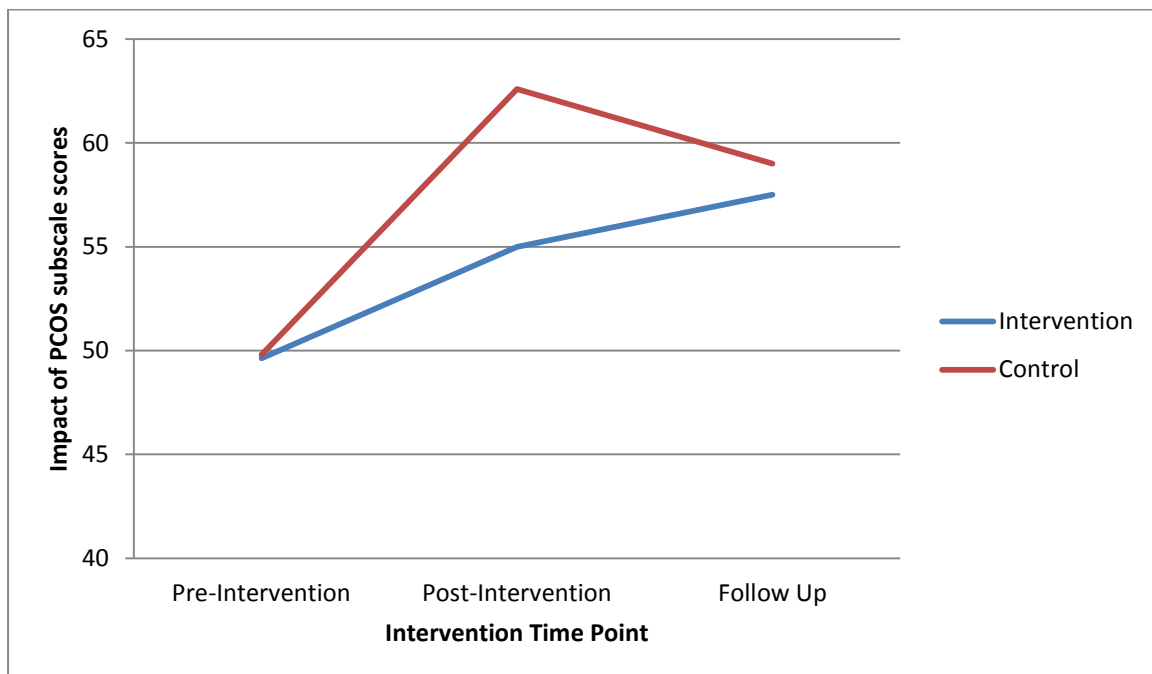


Figure 7.3 PCOSQOL Impact of PCOS subscale scores across all three time points.

For the Mood subscale, Mauchly’s Test of Sphericity indicated that the assumption of sphericity had been violated, $X^2(2)=9.368$, $p<.05$, and therefore a Greenhouse-Geisser correction was used. A 2x3 mixed design ANOVA found no significant main effect of the time point that participants completed the PCOSQOL subscale of ‘Mood’ (pre, post and follow up), $F(1.271,15.255)=1.556$, $p=.24$, $r=0.30$. There was also no significant interaction effect between the time point the Mood subscale was completed and the group (control or intervention) $F(1.271,15.255)=.434$ $p=.57$, $r=0.17$. There was no significant effect of group,

indicating that Impact of PCOS scores from the intervention and control group were similar, $F(1,12)=.155$, $p=.70$, $r=0.11$.

For the Infertility subscale, Mauchly's Test of Sphericity also indicated that the assumption of sphericity had been violated, $X^2(2)=9.342$, $p<.05$, and therefore a Greenhouse-Geisser correction was used. A 2x3 mixed design ANOVA found no significant main effect of the time point that participants completed the PCOSQOL subscale of 'Infertility' (pre, post and follow up), $F(1.244, 13.689)=3.099$, $p=.09$, $r=0.43$. However, scores on the Infertility subscale were significantly higher at follow up than at baseline, $F(1, 11)=5.648$, $p<.05$, $r=0.58$ (Figure 7). There was also no significant interaction effect between the time point the Infertility subscale was completed and the group (control or intervention) $F(1.244, 13.689)=.366$, $p=.60$, $r=0.47$. There was no significant effect of group, indicating that Infertility subscale scores from the intervention and control group were similar, $F(1,11)=.304$, $p=.593$, $r=0.16$.

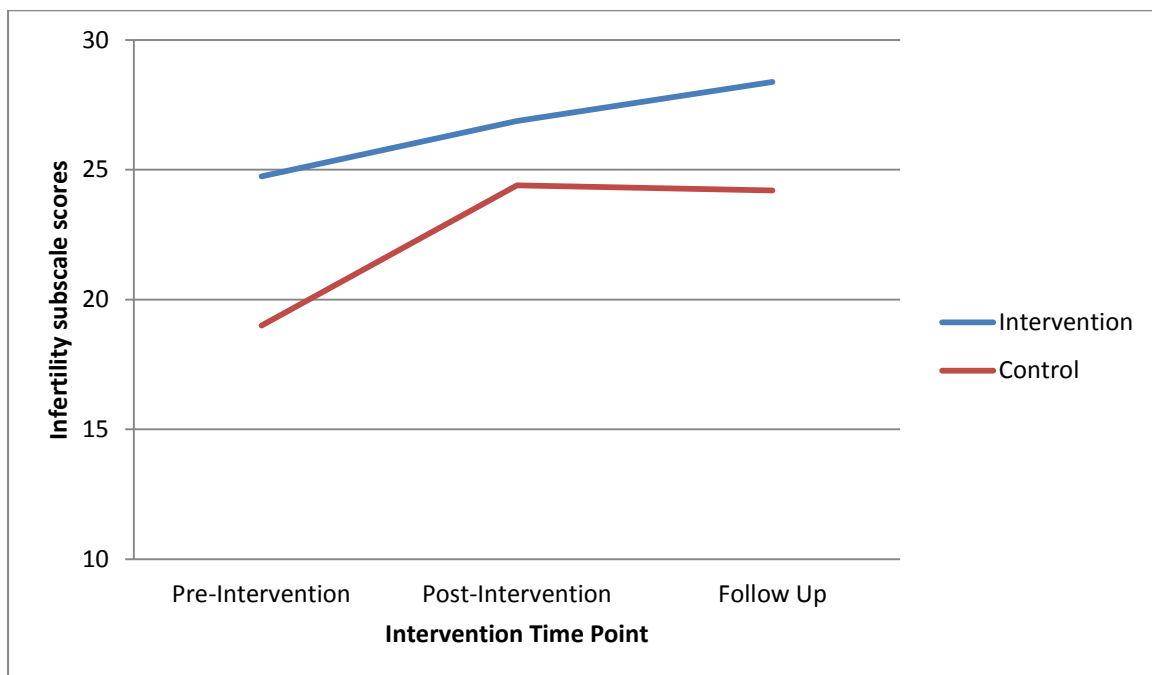


Figure 7.4 PCOSQOL Infertility subscale scores across all three time points.

In summary, analyses revealed that there was no interaction effect between condition and the time (pre and post intervention and follow up) that participants completed the PCOSQOL scale, or any of its subscales.

7.3.2 HADS

A mixed design ANOVA found no significant main effect of the time point that participants completed the HADS depression measure (pre, post and follow up), $F(2,22)=1.541$, $p=.24$, $r=0.23$. There was no significant effect of group, indicating that depression scores from the intervention and control group were similar, $F(1,11)=.16$, $p=.701$, $r=0.12$. There was also no significant interaction effect between the time point the HADS depression measures were completed and the group (control or intervention) $F(2,22)=.251$, $p=.78$, $r=0.11$.

There was also no significant main effect of the time point that participants completed the HADS anxiety measure (pre, post and follow up), $F(2,22)=.705$, $p=.51$, $r=0.18$. There was no significant effect of group, indicating that anxiety scores from the intervention and control group were similar, $F(1,11)=.033$, $p=.86$, $r=0.05$. There was also no significant interaction effect between the time point the HADS anxiety measures were completed and the group (control or intervention) $F(2,22)=.354$, $p=.71$, $r=0.13$.

7.4 Evaluation

Twenty participants provided evaluative feedback of the study from both the control ($n=9$) and the intervention ($n=11$) group. Participants have been identified by a letter in the quotes below and the condition (intervention or control) they belonged to highlighted.

Of the participants in the intervention group who took part in the activity ($n=29$) only two participants completed the daily three good things activity each day for the duration of the intervention. Moreover, only 12 of those women who took part completed 50% or more of the three good things intervention and 10 women completed less than 25% of the of the three good things intervention over the four week period.

The majority of participants ($n=7$) found the intervention 'Very Easy' to complete (control $n=3$, intervention $n=4$). Two participants found the intervention 'Very Difficult' to complete; both of these participants were in the control condition. Of the participants who found the study 'Very Difficult' both also stated that 'No I didn't enjoy it' when asked if they had enjoyed taking part in the intervention. One of these participants provided further feedback:

“I didn’t even receive questionnaires or interventions through! I think I was asked to complete one initial questionnaire and that was it to my recollection. I’ve checked my inbox and also my junkmail folder and nothing came in that I can see.”

[Participant A, Control]

“Maybe actually ensuring questionnaires/intervention tasks have been sent would help in your research!” [Participant A, Control]

This participant raises an important issue in online research as there is no way for researchers to ensure that emails are successfully delivered to participants in online based interventions. Participant B, similarly states:

“The emails didn’t always arrive” [Participant B, Control]

They highlight the need for researchers to check successful delivery of emails; this may be done by requiring that the participants confirms that they have the read the email either voluntarily or through ‘a delivery receipt’ which informs the sender of the email that it has been delivered. However, this latter suggestion is ethically problematic as it breaches the participant’s privacy, whereas the former suggestion requires the participants to complete extra activities which could contribute to them withdrawing from the study due to the impact on ease of use. It is also worth noting that this participant appears confused about their role as a member of the control condition; she states that she did not receive ‘interventions’, however as a member of the control group she would not have had any. Therefore, in future interventions participants should be advised to contact the research team if they have not heard anything at the data collection time points.

Largely, participants reported a positive experience of taking part in the intervention:

It helped to inforce positive feelings about myself... [Participant C, Intervention]

it was nice to sit down at the end of the day and think of good things that happened that day.

[Participant D, Intervention]

it made me aware of my own positivity and the importance of considering my activities, and the effect these will have on my physical health and wellbeing [Participant E, Intervention]

Consciously thinking about positive things really helped me appreciate things, even on days where I felt completely hopeless [Participant F, Intervention]

The participants above demonstrate the direct impact of taking part in the three good things activity, despite the lack of significant findings in this study. Moreover, two participants in the control group (from n=4) had a positive experience in taking part in the study:

It made me think that there is more to life than worrying about PCOS. [Participant G, Control]

Made you think of only good things [Participant H, Control]

This supports the statistical finding that simply being part of the online positive psychology intervention, regardless of condition, can have a positive impact on participants who take part. In contrast, Participant I found it more difficult to complete the daily three good things activity, even though they enjoyed aspects of the intervention. Participant L also found it difficult to think of three good things each day, they state:

On my “down” days I found it very difficult to find a positive about my day. As I am trying to live with infertility but am desperate for a child, nothing seems to be a help. I did reflect on my day when filling out my daily positive and thought about how many people I am grateful to have in my life. [Participant I, Intervention]

Sometimes it was hard finding 3 things each day... [Participant L, Intervention]

Eight participants in the intervention group had incomplete entries for their three good things activity, often only stating one good thing or writing ‘nothing’, ‘none’ or ‘cant think of anything’. This suggests that other participants may have found it difficult to think of three good things each day of the intervention. As Participant I states that this occurred for her on her ‘down days’, it may be that the participants depressive symptoms make it difficult for her

positive aspects of her day. She suggests that future interventions should allow participants to describe their emotions for each day:

Possibly the next survey could have a box for emotion for the individual to express how they feel each particular day along with their 3 positive outcomes [Participant I, Intervention]

This would allow the research team to further understand of how, and if, participants' mood and emotions impact their completion of the three good things activity.

One participant who found it difficult to think of three good things each day discontinued their participation in the three good things activity as it made her 'unhappy', she states:

I found it difficult in my current situation (unemployed, astranged from family) to come up with any sort of substantial positive. Those that I did think of remained constant day to day, and reminding myself of that only served to make me feel more aware that my situation was not changing. I discontinued the study because it made me unhappy. [Participant M, Intervention]

The quote above suggests that participants may have voluntarily discontinued their participation in the three good things activity; this may account for the lack of completion of the daily activity across the intervention condition. Other reasons for non-completion may include the length of time the intervention required to complete, both for the completion of questionnaire measures and the three good things activity, and also the difficulty in remembering to take part in the activity. This is demonstrated by the participants below:

...the only problem I found was remembering to fit it in my normal routine! [Participant C, Intervention]

it made me think of positives in my life which was very good for me but some questions were very repetitive on the longer questionnaires [Participant J, Intervention]

It was easy enough to do just took a bit of time logging in etc. was thought provoking trying to think of positive aspects of my day. Don't really feel it made a difference to my life or how I feel though [Participant K, Intervention]

...sometimes I forgot as the email came through quite early in the day and by the time I had 3 things it was the evening and I forgot to fill the form in [Participant L, Intervention]

It was hard to keep up [Participant B, Control]

Participants discussed how the intervention took ‘time’, was ‘hard to keep up’ and one lady described how she ‘forgot’ as she received the email reminders early in the day.

It was difficult to keep up with, remembering to do it! Some sort of text alert would have helped – equally, with hindsight, I could have set a reminder” [Participant E, Intervention]

7.5 Discussion

This study aimed to explore the impact of an online positive psychology intervention on quality of life and levels of depression and anxiety. Analyses of the data for all measures revealed that there was a significant main effect of the time point that participants completed measures, specifically from baseline to follow up for overall quality of life scores and scores on the PCOSQOL subscales, Impact of PCOS and Infertility. However, the intervention activity had no impact on quality of life scores or depression and anxiety scores. These results, in combination with an analysis of descriptive statistics suggests that being part of the study may have had an impact on participants scores of quality of life and depression regardless of taking part in the three good things intervention.

The descriptive statistics suggest that the mean scores of depression decreased from baseline to follow up; however, no significant difference was found. Interestingly, the mean scores of anxiety for the HADS subscale ranged from 8 to 10 across the three measurement times: according to Snaith (2003), this is suggestive of the presence of anxiety. A mixed model 2x3 ANOVA, however, found no differences in anxiety scores between groups, and across time points. This suggests that a positive psychology intervention whilst being effective in reducing scores of depression (Seligman et al., 2005) may not be effective in reducing symptoms of anxiety. Participants scores on the HADS depression subscale, however, were considered normal, with all mean scores for both control and the intervention group, at each time point, being below 7 (Snaith, 2003). This is similar to the findings of Sin and Lyubomirsky (2009) who suggested that there may be a ‘floor-effect’; participants with low levels of depression

do not experience much improvement in levels of depression and so larger or more selective samples may afford better tests of positive psychology interventions in women with PCOS.

There was a low retention rate in this study; this is similar to Manicavasagar et al. (2014) who also experienced difficulties maintaining high levels of adherence and low levels of attrition. Chi square analyses suggest that there is an association between participants who experienced the symptom mood swing or not, and participants who did not take part in the study after randomisation. To improve this, future research should employ text messaging or mobile phone applications to run the intervention, as discussed by participants in the *Evaluation* section of this chapter. The low retention rate for this study led to a small sample size which was a limitation for this intervention. However, post-hoc power analyses conducted in G*Power revealed that for the sample size of 14 for a 2x3 ANOVA and an effect size (f) of 0.53 and a non-sphericity Epsilon value of .643, a power of 0.69 was achieved; this suggests the study was underpowered. A priori power analyses revealed, with the same effect size (f) of 0.53 and a non-sphericity correction of .643, to gain a power of 0.9, a sample size of 24 would be needed. Given a retention rate of 18%, future studies should there aim to recruit at least 135 participants to achieve a power of 0.9.

Several participants in this study only entered items on the three good things activity that related to their symptoms. It is feasible, therefore, to assume that participants may not have understood that they were able to write about any three good things that happened to them that day, and not just those good things which were related to PCOS. This may have meant that participants felt limited in what they could enter for the activity and therefore, they may have not completed the three good things activity each day. Whilst participants were given examples of good things they could choose which were outside of their condition, future research should ensure that participants are reminded of this throughout the intervention. Similarly, *Evaluation* revealed that some participants found it difficult to think of three good things. Indeed, several participants entered 'none', 'nothing' or did not complete the three entries for the daily activity. As such, not all participants in the intervention group consistently entered 'good things' in their three good things activity. Futures studies should seek to complete analysis of the items entered in the three good things activity using a text analysis method such as Linguistic Inquiry and Word Count (Pennebaker, Booth & Francis, 2007); this would afford examination of what participants write about, and if what they write about changes throughout the intervention.

Evaluation feedback suggested that participants should be able to enter their mood when filling in the three good things activity. As such, future research employing a three good things activity should allow participants to describe what type of mood they are in, or what emotions they are experience that day, to further understand the participants experience of the online positive psychology intervention. Moreover, it is evident from the evaluation feedback that the method of intervention delivery could be improved. One way this could be achieved is through the use of mobile technology (mhealth), which are increasingly being used in health psychology research (Arora, Peters, Agy & Menchine, 2012; Akter & Ray, 2010; Cafazzo, Casselman, Hamming, Katzman & Palmert, 2012). Indeed, Rosser and Eccleston (2011) noted that smartphone applications are becoming increasingly popular. Consequently, future research exploring the use of online positive psychology should assess the efficacy of delivering the intervention through a mobile phone application. Similarly, Participant E also suggested that the intervention was ‘difficult to keep up with’, however they suggest that they could have set an alert on their mobile phone to remind them. Moreover, they suggest that a text alert from the research team would have helped to remind here to take part in the study.

The use of text message reminders in health behaviour change research is increasingly common (Armstrong et al., 2009; Sims et al., 2012; Zurovac et al., 2011). Indeed, Pop-Eleches et al. (2011) suggest that text message reminders improve adherence to treatment in individuals with HIV. Similarly, Petrie, Perry, Broadbent and Weignman (2011) concluded that targeted text messages increased adherence to use of an asthma preventer inhaler. Further, Cole-Lewis and Kershaw (2010) state that text messaging may improve existing practices and interventions and may be an important took in providing more effective disease management support. As such, future research should aim to explore the impact of using text message reminders, over email reminders, for participants in an online positive psychology intervention. Future research should, therefore, explore the use of a text message based service where participants receive reminders and text in their three good things each day to the research team.

Patrick et al. (2009) found that the use of text messages in a weight loss intervention, whereby participants were sent a text message and a response was required to that message, was received well by the participants. This approach, therefore, could also help to overcome some of the limitations of this study, as highlighted by the participants, such as ensuring that

reminders are received (by requiring a response) and by encouraging participation in the study through text message reminders. Therefore, future research exploring the impact of a positive psychology intervention on quality of life in women with PCOS should aim to assess the efficacy of delivering reminders via text message.

One other limitation of this study is that participants were not asked about any life events that may have happened during the study which may have caused participant's to discontinue the study or which may have impacted on participant's quality of life scores and depression scores. Indeed, one participant withdrew from the study when they received an email asking them to complete measures citing difficulties in their personal life which made them feel unable to take part any longer.

As recruitment for this study took place online, participants self-reported whether they met the inclusion criteria which specified that those with mental incapacity or those unable to give informed consent would be excluded from taking part in the research. As such, it was not possible to guarantee that those participants who took part in the study did or did not meet the inclusion criteria. Future research is therefore necessary using a clinical sample in order to have more control of the participant sample.

During recruitment for this study it became evident that one of the Facebook groups had begun to run their own weekly, three good things activity (possibly as a result of hearing about this study). Members of the group would 'comment' on a post by the administrator, and list three good things that had happened to them that week. Whilst it is unclear exactly whether participants in this research took part in the Facebook activity, it is possible that participants in this study may have taken part in the weekly activity as well. This is particularly important when considering the impact this may have had on members of the control group and the analyses of descriptive statistics that revealed improved quality of life of scores for participants in the control group and the intervention group at baseline to end of study. Future studies should ensure they expressly advise participants not to take part in any similar gratitude activities whilst completing the study to avoid this. Alternatively, participants in the control group could complete a placebo activity.

Within this study participants in the control group were not given an activity to complete, but were asked to fill in the relevant measures at each time point. In perhaps the most notable

three good things intervention, Seligman et al. (2005) asked participants in the control group to write about their early memories. Writing about early memories as an activity for the control group has since been used by other researchers utilising the three good things activity (Gander, Proyer, Ruch & Wyss, 2012; Mongrain & Anselmo-Matthews, 2012). Other control activities used in gratitude interventions within the positive psychology literature include writing about daily life events (Emmons & Mccullough, 2003) whereby participants write about things that they have done that week. However, this was later replicated by Martinez-Marti, Avia and Hernández-Lloreda (2010) who suggested that this was not a suitable control group as participants wrote about more positive things than neutral ones, thus potentially mimicking a positive writing intervention. Other research, similarly to the study reported in this chapter, have not provided any alternative activity for the control group during the trial (Schueller & Parks, 2012) and simply taken measures from participants at the appropriate time. As such, development of this pilot trial should consider using a neutral but similar task to the three good things activity, such as writing down three daily events (Emmons & Mccullough).

This pilot RCT was also limited as it was an open trial, meaning that all participants were given information about the intervention activity (Schulz & Grimes, 2002). Schulz and Grimes suggest that knowledge of an intervention and perceptions of it can have an impact on the psychological responses of participants. As such, the results of this study need to be interpreted with caution, as it is possible, as detailed above, that a participant in the control group could have undertaken the three good things activity during the study. Previous positive psychology interventions have previously implemented blinding of subjects to the condition they have been assigned (Emmons, 2006; Lyubomirsky, 2011; Seligman, 2005; Sheldon, 2002, 2006). Future research should, therefore, employ a minimum of a single-blinded randomised controlled trial which ensures that the participants do not know which group they belong too (Karanicolas, Farrokhyar & Handari, 2010; Schulz & Grimes). By including a placebo activity, as discussed above, participants can be told that they will be asked to write each day but no detail with regards to whether they are writing three good things, or writing for a placebo activity needs to be given, this may mean that any findings are due to the intervention.

Whilst this pilot study did not find an effect of utilising a three good things activity, a study with a larger sample may find improvements in quality of life in women with PCOS. Future

research should assess the effectiveness of this intervention in a larger sample of women with PCOS. Moreover, future research should explore the utility of using text-message, or mobile phone applications, in positive psychology interventions; particularly with the three good things activity.

Chapter Eight -General Discussion

This thesis aimed to further understanding of, and improve quality of life, of women with PCOS, including those who live with co-morbid conditions. To achieve this, it aimed to investigate and identify how women with PCOS in the UK perceive and define their quality of life; to further understanding of the impact of PCOS on quality of life from their perspective; to explore and gain an understanding of how women with PCOS in the UK live with and perceive their condition and any co-morbid conditions on a daily basis; to develop and test a disease-specific quality of life scale for women with PCOS in the UK; to identify and investigate the prevalence of PCOS symptoms and co-morbid conditions in women with PCOS and their association with quality of life; and finally, to identify, develop and test a pilot intervention aimed at increasing quality of life in women with PCOS who may present with symptoms of depression and/or anxiety.

This chapter will build on the discussions of the previous chapters and provide an overall discussion of the thesis. It will begin with a summary of the main findings, and it shall then discuss the contribution of this thesis to wider knowledge with regards to coping in long-term conditions and quality of life. Moreover, this chapter will discuss the methods used for recruitment and data generation. It shall continue with a discussion of the strengths and limitations of this thesis, recommendations for individuals working in clinical practice and future directions. Finally, reflections of this PhD and the overall conclusion shall be discussed.

8.1 Summary of Main Findings

This thesis began with an exploration of the impact of PCOS on quality of life, from the participant's perspective and utilised a photovoice methodology (chapter three). This chapter identified three main themes: Control (Symptom Management and PCOS as Controlling), Perception (Feminine Identity and Positive Outlook) and Support (The Health Care System, Education and Relationships). Some of the themes detailed in this chapter have been discussed in previous research including the theme Symptom Management (Crete & Adamshick, 2011) which discusses the methods used by women with PCOS to manage their symptoms. This can include diet, exercise, medication and hair removal techniques. Another theme which has previously been discussed in the literature is the theme Feminine Identity. This theme concerns the way women with PCOS feel that the condition and its symptoms,

impact on their identity as a women. In particular, this relates to the symptoms of infertility (feeling they are not a real woman due to their inability to conceive) and hirsutism (feeling they are more masculine than feminine due to their hirsutism symptoms).

Another theme that has been touched upon by previous literature, although not explicitly discussed, is the theme PCOS as Controlling (Percy et al., 2009; Snyder, 2006). The theme demonstrated how women with PCOS felt like they had a lack of control over their condition, and its symptoms, which often lead to participants becoming socially isolated. There were, however, several original findings within this chapter; this includes the theme of Positive Outlook which pertains to the way in which women with PCOS retained an optimistic outlook despite living with their condition and its symptoms. In particular, it revealed how women with PCOS remained optimistic about their condition, particularly their future fertility.

The overarching theme of Support has been discussed in the previous literature (Holbrey & Coulson, 2013; Percy et al., 2009). Within this theme, the sub-theme Health Care Professionals discussed the lack of support women with PCOS felt they received from their health care professionals (Crete & Adamshick, 2011; Kitzinger & Willmott, 2002; Snyder, 2006). This was the first study to discuss how women with PCOS used online support groups held on social networking websites such as Facebook, and online blogging websites such as Tumblr, to gain support from other women with PCOS and to find information about their condition, particularly when this information was not forthcoming from their health care professional. Moreover, whilst the role of pets and support has been discussed in the wider literature (Allen, 2003; Allen et al., 2002; Antonacopoulos & Psychyl, 2010); the study within this thesis was the first to reveal the supportive role pets played for women with PCOS with one participant referring to their cat as their 'furry baby'.

The Skype™ interview study detailed in chapter four found four major themes: Change (To Life Plans and Changing Nature of the Condition), Co-Morbidities (Living with Other Conditions and Depression and Self-harm), Support (Health Care Professionals, Self-support and Relationships) and Self (Feminine Identity and Us and Them). Women in this study, within the theme Support, also felt that they did not get enough support from their health care professionals and, as detailed in Chapter Four, they found themselves searching for the information and described gaining support from women in online social networks such as

Facebook. In addition, this study found a theme of Feminine Identity (similar to chapter three). Findings in the interview study supported those of the photovoice study in Chapter Three, however, the impact of PCOS on the participant's identity did not pertain just to their feminine identity but also to their perception of themselves as broken.

In the interview study in Chapter Four two themes that held original findings were detailed: Change and Co-Morbidities. The theme Change discussed the impact the condition had on the participants' life plans, often resulting in women having to change their life goals, to focus on family planning, or from their plan of having a family to not being able to. Moreover, some participants reported that they felt under pressure to conceive, with one participant specifying that this pressure came from their health care professional. This is the first time that pressure to conceive, and pressure from a health care professional to conceive, for women with PCOS has been reported.

Another theme reported in this chapter is that of Co-morbidities. Within this chapter, six participants reported experiencing at least one co-morbid condition to their PCOS including thyroid disorders, hypermobility and IBS. Whilst these conditions have been explored in relation to PCOS in the medical literature (Janssen, Mehlmauer, Hahn, Öffner & Gärtner, 2004; Mathur et al., 2009; Sinha et al., 2013), this is the first study to explore how women with PCOS who also have a co-morbid condition, experience living with more than one long-term condition on a day-to-day basis. In addition, two thirds of the participants reported experiencing psychological co-morbidities, or depressive symptoms, including self-harm. The prevalence of depression in women with PCOS has been previously documented (Deeks, Gibson-Helm & Teede, 2010; Månsson et al., 2008; Rassi et al., 2010). However, the study described in Chapter Four of this thesis is the first to discuss how women with PCOS experience living with their condition and psychological co-morbidities, such as depression. Furthermore, this chapter also demonstrated that women with PCOS seek support online from social networking websites such as Facebook where they gain not only support from other women with PCOS but also information. Chapter four, therefore, furthers understanding of the experience of living with PCOS and co-morbid conditions, on a day-to-day basis.

The findings of Chapter Three and Four also aided in the development of items for a disease-specific quality of life measure, the PCOSQOL, detailed in Chapter Five. Example items of the PCOSQOL include: 'Felt under pressure to have a child', 'Felt like you weren't a real

woman because of your PCOS’, ‘Felt like you don’t know what to do to control your PCOS’ and ‘Struggled to cope with your PCOS and other condition(s)’. The items included in the development process pertained to all domains of quality of life as detailed by the WHOQOL group (1994), including: social, environment, level of independence, physical health and psychological health. The initial 62-item prototype scale was reduced to a 35-item scale after item reduction, the scale was then subject to validity and reliability testing (as detailed in chapter five). The final PCOSQOL is made up of 35-items and four subscales: Impact of PCOS, Infertility, Hirsutism and Mood. This scale was developed on and for a UK population, overcame some of the criticisms of the PCOSQ and had excellent reliability and good construct validity. Information about the validity of the PCOSQOL was also sought and tested as part of Chapters Six and Seven (Nunally, 1994; Streiner & Norman, 2008)

This thesis also aimed to investigate the prevalence of symptoms and co-morbid conditions, in women with PCOS in the UK. As two thirds of the women in chapter four discussed their psychological co-morbidities, particular focus was placed on the prevalence of psychological co-morbidities over physical. This thesis then also aimed to explore the association of these symptoms with overall quality of life. As such, data was gathered from women with PCOS during the scale development study, which included their quality of life scores from the PCOSQOL. Many of the demographic questions were based upon the findings of the studies in chapter three and four: this included questions around participants’ past clinical diagnoses of depression and anxiety, and symptoms they experienced. Analyses, detailed in chapter six, revealed that women with PCOS who experienced the symptoms of infertility, hirsutism, weight, alopecia, skin discolouration, skin tags and mood swings had significantly lower quality of life scores than those women who did not experience the symptoms. These findings suggest that quality of life for women with PCOS may be mediated by the symptoms they experience. This analysis also helped provide information with regards to the validity of the PCOSQOL as the measure was able to identify differences in quality of life within the sample of women with PCOS.

There were key findings in chapter six: primarily, analysis of the data revealed that the symptom of skin tags may be a more prevalent symptom of PCOS than previously reported (Lowenstein, 2006). Indeed, the symptoms which impact physical appearance including alopecia, skin discolouration and skin tags, were all significantly associated with a self-reported clinical diagnosis of Social Anxiety Disorder. Moreover, there were the high levels

of depression and anxiety reported by women with PCOS in the UK, supporting previous research (Bhattacharya & Jha, 2010; Dokras, 2012). These findings further highlighted the need for an intervention to improve quality of life in women with PCOS and also to reduce levels of depression and anxiety.

To improve quality of life for women with PCOS in the UK, regardless of their health care status, a cost-effective, accessible intervention which required minimum input from a health care professional was needed (Bennet, 2004). A positive psychology intervention was identified as having the potential to benefit the most people, with the minimum input (Bennet). As such, a positive psychology intervention would be suitable for those women with PCOS who no longer engage with the wider health care system. A pilot randomised controlled open trial utilising an online positive psychology intervention was therefore developed to explore the impact on quality of life, depression and anxiety in women with PCOS (Chapter Seven).

The open randomised controlled trial consisted of participants in the intervention condition completing the three good things activity (Seligman, Steen, Park & Peterson, 2005) where participants write down three good things that happen to them each day for 28 days. Whilst the study did not find an effect of the three good things activity on quality of life, depression or anxiety; it did find an overall effect of time, meaning that participants (regardless of condition) had significantly increased scores of quality of life from pre intervention to follow up. These results, and analysis of descriptive statistics, suggest that being part of a study may have had an impact on participant's quality of life scores regardless of the condition they were randomised to. No interaction or time effect was found for scores of anxiety and depression.

8.2 Quality of Life

The overarching objective of this thesis was to further understanding and improve quality of life in women with PCOS which includes those who live with co-morbid conditions. Specifically, this thesis also aimed to explore how women with PCOS in the UK perceived and defined their quality of life (Chapter Three). With regards to quality of life for women with PCOS in the UK, the qualitative studies of this thesis demonstrated that women with PCOS perceived their quality of life to be made up of aspects relating to their physical health (e.g., the experience of symptoms) and psychological health (e.g., negative feelings and

bodily image), social concerns (e.g., relationships and social support), their environment (e.g., participation in recreation and financial resources) and their independence (e.g., activities of daily living and their dependence on medications/treatments). These concerns reflect those domains of quality of life reported by the WHOQOL Group (1994). In addition, the women in the qualitative studies maintained a positive outlook, particularly demonstrated by Denise who found a story in the newspaper about a successful pregnancy after many miscarriages, gave her hope. Through this positive outlook, the women in these studies also demonstrated aspects of optimism and hope which reflect the spirituality, religion and personal beliefs domain of quality of life (WHOQOL Group, 1994).

The findings of this thesis demonstrate that quality of life, for the women with PCOS in this research reflect those of the WHOQOL Group (1994). However, although items pertaining to all these areas of quality of life were included in the prototype 62-item scale, many of them were discarded through the scale development process of item reduction. This suggests that those domains most represented by items included in the final PCOSQOL best reflect the areas of quality of life deemed important to women with PCOS in the UK. That is the physical, psychological and social domains of health. As such, quality of life as defined by women with PCOS in the UK would reflect those domains of quality of life identified by previous research (Fallowfield, 1990; Fayers & Machin, 2007; Testa & Simonson, 1996).

In addition to furthering understanding of how women with PCOS in the UK perceive and define their quality of life, and the day-to-day to experience of living with PCOS, the findings of this thesis demonstrate that PCOS can have a negative impact on quality of life for women with PCOS in the UK. Moreover, it found that women with PCOS who experience the symptoms of infertility, hirsutism, weight, alopecia, skin discolouration, skin tags and mood swings had a lower quality of life than women who did not experience these symptoms. This suggests that effective management and/or treatment of these symptoms may improve quality of life for the women who experience them.

8.3 The Feminine Role

For the participants of this research, PCOS permeated all the levels of their life (Radley, 2004). However, the impact of PCOS on the participants' perception of themselves as a woman, and on their ability to have children, was discussed in each qualitative study and was of notable importance in the scale development study through the inclusion of items 'Felt like

less of a woman because of having PCOS' and 'Felt like you weren't a real woman because of your PCOS' in the PCOSQOL, demonstrating their importance to quality of life for women with PCOS.

8.3.1 Feminine Identity

Within the qualitative chapters of this thesis it became evident that PCOS has a negative impact on the participant's sense of identity as a woman. In both the qualitative chapters, participants discussed how the symptoms of hirsutism, and the symptoms relating to menstrual regularity and fertility, impacted their identity as a woman. In addition, items pertaining to feminine identity in the scale development chapter were endorsed by many of the participants, and were included in the final PCOSQOL. This suggests that PCOS symptoms which impact a woman's feminine identity are related to their quality of life, however, the exact nature of this relationship is unclear.

Farkas et al. (2014) suggest that women with PCOS perceive themselves as unable to conform to the traditional feminine social norm due to the impact of PCOS on their appearance. Farkas et al. specify the symptoms of hirsutism, menstrual cycle abnormalities and infertility as impacting on their sense of femininity. Similarly, Kitzinger and Willmott (2002) were the first to describe the impact of PCOS on a woman's sense of femininity. They detail how their participants referred to themselves as 'freakish' and not 'proper' women (p. 349). Snyder (2006) and Keegan et al. (2003) also reported that women with PCOS could feel less like a woman due to the impact of their hirsutism. Amiri et al. (2014) found that women with PCOS perceived themselves as less feminine due to their hirsutism, menstrual irregularities and infertility. It is probable that these feelings in turn affect the quality of life ratings given by these women.

The impact of infertility on feminine identity is not unique to PCOS and has been observed in women who experience endometriosis and women being treated for cancer (Komatsu et al., 2014; Moradi, Parker, Sneddon, Lopez & Ellwood, 2014), both of which can lead to difficulties conceiving. Moradi et al. (2014) found that women with endometriosis also felt like their condition had a negative impact on their identity as a woman, due to their symptoms of infertility and difficulties having sexual relationships. Similarly, women being treated for cervical cancer, where there is a risk to their fertility, felt that their feminine identity was threatened (Komatsu et al., 2014).

Ireland (1993) suggests that within society there is an assumption that motherhood is intrinsic to adult female identity, as such, women who are unable to become mothers may feel, and be perceived, as missing something. Certainly, Amiri et al. (2014) suggest that health care professionals should initiate management of PCOS which is aimed at reconstructing their womanhood. Furthermore, whilst the impact of PCOS on feminine identity has been discussed in previous research (for example, Keegan et al., 2003; Kitzinger & Willmott, 2002; Snyder, 2006), there has yet to be research which explores this impact of PCOS in any depth, or its relationship to quality of life. As such, future research should seek to explore the impact of PCOS on feminine identity and on quality of life.

8.3.2 Goal Attainment

As mentioned above, women with PCOS can experience difficulties conceiving and having children: as such, their goal to have children can be unfulfilled, as was demonstrated by participants in this thesis. In line with this, Thompson, Woodward and Stanton (2011) propose that individuals with long-term conditions often face challenges to their life-goals. Alongside optimism (discussed in Section 8.3.1 of this chapter), goal adjustment can influence quality of life (Wrosch & Scheier, 2003). Personal goals have been shown to be important factors to an individual's perceived quality of life (DeRidder, 2004). Similarly, Kuijter and de Ridder (2003) suggest that an individual's ability to fulfil a goal is related to their overall well-being. Emmons (2003) also suggests that goal attainment is important for the experience of well-being. This reflects the findings of chapter four whereby the participants, as a result of PCOS, had changed their life plans with regards to having children. Indeed, Kuijter and de Ridder (2003) suggest that when a goal is of high importance to a person, but is not easy to attain, then there may be a negative impact on well-being. They example personal goals in long-term illness, proposing that personal goals related to family may be threatened.

Wrosch and Scheier (2003) suggest that if a relevant goal proves unattainable and there is no possible alternative means to attain the goal, then people should be able to identify an alternative goal, commit to the new goal and initiate activities towards goal attainment. This re-engagement with a goal may contribute to quality of life (Wrosch & Scheier). Salmela-Aro and Suikkari (2008) explored adjustment in women with PCOS with regards to their child-related goals during infertility treatment. They found that goal attainability decreased among

individuals with unsuccessful infertility treatment. Moreover, they report that unsuccessful child-related goal adjustment among individuals with unsuccessful treatment was related to higher levels of depressive symptoms. Therefore, women with PCOS who are unable to fulfil their goals of having children may be at risk of depressive symptomology.

Kraaij, Garnefski and Schroevers (2009) suggest that those people who are involuntarily childless, are in need of help to learn how to cope with their childlessness. Similarly to Salmela-Aro and Suikkari (2008), Kraaij et al. suggest that goal adjustment is necessary to cope with definitive infertility. In addition, Thompson et al. (2011) propose that goal disengagement is adaptive. Health care professionals should, therefore, encourage women with PCOS who are unable to achieve their goal of having children biologically, to come to terms with their goal being unattainable, and commit to a new goal. Moreover, careful attention should be paid to any presenting depressive symptoms in women with PCOS as they adjust their goals.

8.4 Coping in Long-term Conditions

Research suggests that long-term illness has the potential to induce changes in a person's life which can consequently have a negative impact on quality of life (de Ridder, Geenan, Kuijer & van Middendorp, 2008). Similarly, Radley (2004) suggests that when an individual has a long-term condition, then all areas of their life including the physical, social and medical aspects must adapt to the condition. Moreover, Radley proposes that when an individual is coping with their condition, it can become a 'way of life' (p.152). Certainly De Ridder et al. (2008) suggest that performance of adaptive tasks is an element of successful adaptation to long-term illness. Moreover, Kolahi et al. (2015) suggest that inefficient coping strategies negatively impact quality of life of women with PCOS. It is clear, therefore, that coping and adaptation in long-term conditions is related to quality of life.

8.4.1 Optimism

Findings from the first qualitative study suggested that some women with PCOS attempt to keep a *Positive Outlook* (Chapter Three, Section 3.4.2.2). Rasmussen et al. (2009) suggests that keeping a positive outlook, or, being optimistic is a significant predictor of positive health outcomes. De Ridder (2004) suggests that optimists maintain an active coping style which is characterised by problem-focused coping and seeking social support. This was similarly reported by Carver, Scheier and Segerstrom (2010) who report that optimism

predicted active attempts to both change and accommodate to stressful circumstances. De Ridder et al. (2008) propose that a positive mood can positively impact self-management. Similarly de Ridder, Fournier and Bensing (2004) suggest that optimism may promote self-care behaviour. However, Friedman (2002) suggests that it is not clear how optimism relates to a person's degree of psychological adjustment. Research, therefore, suggests that optimism is related to positive health outcomes and active coping styles, although the exact nature of the role is unclear.

There has yet to be research which explores the role of optimism in women with PCOS, however, research into the impact and role of optimism has been undertaken in other long-term conditions (Carver et al., 2005; Deimling, Bowman, Sterns, Wagner & Kahana, 2006). Certainly, initial optimism has been found to predict long-term adjustment in women with breast cancer (Carver et al., 2005). Similarly, research has reported that optimists reported fewer cancer-related health worries than pessimists (Deimling et al., 2006). Moreover, research exploring the contribution of optimism to adaptation with long-term illness found that those with long-term illness, including type 1 diabetes, rheumatoid arthritis and multiple sclerosis, who were optimistic about their health outcomes, showed improvements in mental health over time (Fournier, de Ridder, Bensing, 2002). Future research, should therefore, explore the role of optimism with regards to coping and adjustment in women with PCOS.

8.4.2 Self-Management

Marks et al. (2005) report that individuals with long-term conditions engage with self-regulation, whereby they actively monitor and adjust their medication. Similarly, the participants in the qualitative studies in this thesis described their self-management routines, including: taking medication and supplements to control both internal and external symptoms, hair removal of excess body hair, hair washing routines to protect against alopecia, skin routines to control acne, taking part in exercise and eating a specific diet as a burden. The burden of self-management routines was also highlighted through the inclusion of the item "Spent a lot of time and energy removing excess hair" in the final version of the PCOSQOL, representing the impact of this item on quality of life. This item and the previous qualitative findings support suggestions by de Ridder (2004) and de Ridder et al. (2008) that self-management can take time and effort and can impose a high burden on the individual.

Self-management routines enable individuals to feel in control of their condition (de Ridder, 2004; Leventhal et al., 2003). Indeed, Clark et al. (1991) defined self-management as the daily tasks that an individual must complete to control the impact of their condition, reflecting those tasks undertaken by participants in this study. Additionally, De Ridder (2004) suggests that when a person with a long-term condition develops self-care routines in order to control their condition, it can increase their perceived control of the condition. These self-care routines involve undertaking tasks in order to manage the condition, which could include taking medication, exercising, controlling body weight, eating a specific diet (de Ridder, 2004). Certainly, many women in this study completed adaptive tasks such as performing self-management routines (Moos & Schaefer, 1984). Furthermore, Kuijer and de Ridder (2003) suggest that adaptive tasks (Moos & Schaefer, 1984) may be labelled as illness-related goals (relating to Goal Attainment in Section 8.2.2 of this chapter).

Women with PCOS, therefore, engage with adaptive tasks through performance of self-management routines. For the participants in this study this included taking prescribed medications, taking supplements, controlling the symptom of hirsutism through methods such as shaving and waxing, performing daily skin routines to control acne and also exercising and maintaining a suitable diet. However, there is little research which explores coping in women with PCOS, therefore, future research should explore the methods women with PCOS use to cope and adapt to their condition.

8.4.3 Support

Support was discussed by the participants in this thesis in both the qualitative studies, and its importance was also demonstrated in the scale development study through the final inclusion of support items in the PCOSQOL. This includes items such as ‘wanted to do something but haven’t because of your PCOS’ and also ‘wanted to take part in a social activity but haven’t because of your PCOS’. The qualitative findings of this thesis suggest that women with PCOS may become isolated due to their perception of how other people may react to them (Radley, 2004).

De Ridder (2004) suggests that perceived social support is a better predictor of adjustment than actual support. Moreover, De Ridder (2004) proposes that social support in long-term illness can come in different forms, including: information (what could be done to alleviate the stressor/symptoms), assistance (provision of services), and emotional support

(reassurance and acceptance). Certainly, in this thesis, each of these forms of support were discussed (Chapter Three, Section 3.4.3 and Chapter Four, Section 4.4.3). Of particular note in this thesis was the use of online social media such as Facebook, and attendance at PCOS conferences, to gain support from other women with PCOS.

Social support has been discussed previously in the PCOS literature. Specifically, Percy et al. (2009) suggested that social support was a key factor in mediating the impact of PCOS, and that social support may help women with PCOS to improve their self-management. In addition, Holbrey and Coulson (2013) found that there were many positive benefits for women with PCOS when participating in dedicated online discussion board groups, including a realisation that they were not alone, and facilitating access to advice and information; reflecting the types of support detailed by de Ridder (2004). One additional method of gaining support raised in this thesis was that of gaining emotional support from pets (Chapter Three, Section 3.4.3.3). Within Chapter Three, two participants detailed their pets as having an impact on their quality of life, with one participant referring to her cat as her 'furry baby'. This is in line with research by Allen (2003) who proposed that pets can be important family members to individuals. Indeed, whilst this is the first study exploring PCOS to report the supporting nature of pets, previous research has detailed how pets can act as support in health experiences (Allen et al., 2002; Ryan & Ziebland, 2015).

Mousiolis, Michala and Antsaklis (2012) report, use of the internet and social media has now largely replaced the health care professional as the main source of information for individuals with PCOS. Avery and Braunack-Mayar (2007) similarly suggest that for women with PCOS the internet was the most versatile and beneficial source of information. Moreover, Dowdy (2012) reported that many teenagers with PCOS used the internet for guidance and support, when they found their health care professional lacking. This suggests that women gain informational support as well as emotional support, from other women with PCOS and the internet. There remains a need therefore, for more research which explores the role of social support for women with PCOS, particularly in relation to how they make use of the internet and social media support groups.

8.5 Psychological Co-morbidities

This thesis aimed to further understanding and improve quality of life for women with PCOS. However, many of the participants reported experiencing co-morbid conditions in addition to

their PCOS. Specifically, within Chapter Four, of the nine participants with PCOS who took part six participants experienced a physical co-morbidity, these included: migraines (n=1), IBS (n=1), hypermobility (n=1), hypothyroidism (n=1) and adrenal fatigue (n=1). Of note, however, six participants reported experiencing symptoms of depression. Of these participants three experienced both a physical co-morbidity and a psychological co-morbidity (Dawn, Kay and Tanya).

Previous research has suggested that individuals with long-term conditions are likely to experience depression and anxiety (Marks et al., 2015). For women with PCOS, this is also shown to be true as women with PCOS are more likely to experience increased levels of anxiety and depression in comparison to women without PCOS (Benson et al., 2009; Cipkala-Gaffin et al., 2012; Deeks et al., 2011; McCook et al., 2005). Certainly, Coffey et al. (2006) suggest that PCOS can impact women more psychologically than physically. This was reflected by participants in this thesis and the initial 62-item prototype scale, which included items regarding the experience of living with co-morbidities and psychological co-morbidities. Whilst not all of these items remained after the item reduction procedures, the item 'felt overwhelmed by your PCOS and depression' and 'struggled to cope with your PCOS and your other condition(s)' did remain. This suggests that living with PCOS and depression or other co-morbid conditions, is a key aspect of quality of life for women with PCOS in the UK.

De Ridder et al. (2008) suggest that symptoms of depression and anxiety can interfere with self-management routines. De Ridder et al. also report that absence of psychological disorders is an element of successful adjustment to a long-term condition (in addition to performance of adaptive tasks). However, as many of the participants in this thesis presented with psychological disorders of depression and anxiety and it suggests that a number of women with PCOS in the UK may not have successfully adjusted to their PCOS. Benson et al. (2010) report that in women with PCOS, maladaptive coping is associated with anxiety and depressive symptoms and also reduced quality of life. As such, further research is needed which explores the impact and role of psychological co-morbidities such as depression and anxiety in women with PCOS, on coping.

8.6 Methods

There were several little-used methods used in this thesis, including online research methods to recruit participants and collect data and also photovoice as a data generation method.

8.6.1 Online Research

The majority of research for this thesis was conducted online, including recruitment, data generation and data collection: in the photovoice study, participants were recruited via a post on the PCOS charity Verity, and communicated with via email; in the Skype™ study participants were interviewed online and in the third and fourth study, participants' data were collected entirely through online questionnaire software (LimeSurvey and Qualtrics). With the exception of Chapter Three, whereby participants were recruited via a post on the Verity website, participants were recruited entirely online through online social networking website Facebook using PCOS support groups in the UK. Verity were unable to facilitate recruitment for the latter three studies detailed in this thesis.

Each of the Facebook support groups had several hundred women with PCOS as members and at least one, if not more, administrators of the group. The administrators were responsible for maintaining order within the group, including deleting sales posts which were trying to sell products and deleting comments, or closing 'threads' where members of the group had begun to argue. Each of the administrators was a volunteer and used their own time to help provide a supportive area for the women in their group, and they were crucial for this research, as without their permission, recruitment would not have been possible. However, these women, and often the members of the groups, went above and beyond to help support this research; often 'pinning' recruitment posts to the top of the group or 'bumping' recruitment posts to ensure that they stayed visible to members of the group. Participants who had or were taking part in the research would also recommend the research to other women in the group and encourage them to take part. This is demonstrated in the quote below regarding the online positive psychology intervention (Chapter Seven), from a member of one of the Facebook groups:

If anyone's thought about taking part in Sophie's research, I'd recommend it. I've been struggling recently to stay positive and this helps me focus on recognising positive things each day [Participant A]

This feedback demonstrated direct impact of taking part in the study to participants. This is reflected in the quotes below, written in response to the recruitment post for the scale development study (Chapter Five):

I already have done it, and thinking about the answers made me realise how much it is actually affecting me emotionally! So it gave me the push to go back to the doctors and admit that they was right, I am depressed, and taking it out on other people closest to me, so Thank you! ☺ [Participant B]

I completed the survey and I must say that the questions were really well thought out. Some of them made me realise that I can't be the only one feeling like I am. I just hope one day that doctors will have a better understanding of this condition so that they can better support women. It isn't just an isolated symptom, it impacts on ever area of your life. I am so happy that something is being done! [Participant C]

Completed it for you now Sophie, I was so happy to be being asked those questions because no medical professional has ever asked me those questions yet the answers to those questions are a huge part of PCOS – it's so sad that health care professionals do not indulge themselves with PCOS when the facts are that 1in10 women have PCOS – so frustrating! ☹
..... [Participant D]

When participants posted comments as above, they were asked if it would be okay for the quote to be used (anonymously) in this thesis. Every participant said yes, and some added more, for example:

Sure I would love that because I feel very strongly about this research being right and coming into fruition I have been trying to conceive for 9 and half years and been pushed from pillar to post if I can help prevent that happening to someone else then be my guest ☺x
[Participant D]

This visible, positive impact of the research on participants helped reaffirm the need for, and importance of, this research. Moreover, over the course of the research, recruiting participants from Facebook became easier as group administrators began to recognise the researcher's name and became familiar with the research. Indeed, as the research progressed and studies

were completed, the Facebook groups and those individuals who participated were updated on the research and any subsequent publications or conference presentations. Upon completion of all the studies, a summary of the research findings was posted to the groups that had allowed recruitment to take place. In this way, the participants have been involved ‘full-circle’ with this research and its findings. These posts received many ‘likes’ and also several comments. One member of the groups said:

Well done Sophie and thank you so much for your work to bring better understanding of what it's like to live with PCOS.

Its good to hear that research is being done for awareness.

Other aspects of this research were also carried out online, including data collection; the interviews in Chapter Four were carried out on Skype™ and in Chapter Five, Six and Seven data were collected using online survey software, including LimeSurvey and Qualtrics. Whilst completing data collection online had many benefits including being cost and time effective, it did lead to several problems with data retention, particularly in the scale development study detailed in Chapter Five.

Whilst software errors may be frustrating, there will always be an element of human error to online research. The responsibility to check each day that there are no errors with the software lies with the researcher. Certainly, one of the biggest lessons learnt whilst completing this research was how one small software error could have a large impact on the research. Therefore, when conducting online data collection, researchers should be aware of the possibility of errors in the data collection software. However, due to these events, it has since been possible to advise other students on potential problems they may encounter in online research, and how to prepare for them. For example, giving advice to a student on possible issues they may encounter when conducting Skype™ interviews and how to prepare for them.

8.6.2 Photovoice

In addition to Facebook, participants also communicated through other means such as taking photographs and keeping diaries. One participant included a ‘Thank you’ note in the diary they completed as part of the photovoice study. The thank you note was not the only

interesting, and unexpected, way that participants used their diaries. In the photovoice study, two of the nine participants used their diaries to draw diagrams that represented various aspects of themselves; one was a diagram of the participant's changing sexuality and the other was a diagram of the participant's perception of their body (see below).

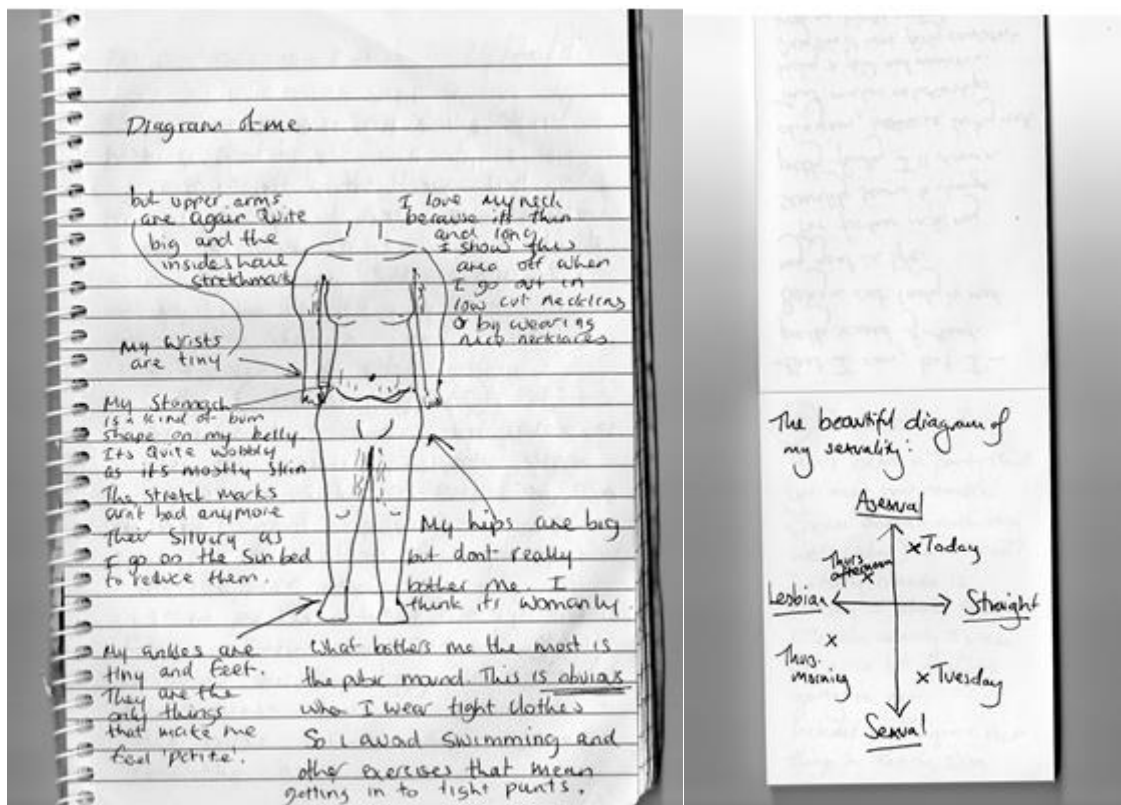


Figure 8.1 Example of Diagrams from participant's diaries detailed in Chapter Three

Whilst diagrams have been previously used for data collection (Umoquit, Tso, Burchett & Dobrow, 2011; Umoquit, Tso, Varga-Atkins, O'Brien & Wheeldon, 2013), a literature review revealed that the spontaneous use of diaries to draw diagrams/figures by participants in photovoice research had not previously been reported. Interestingly, at the Midlands Health Psychology Network Conference (2014), Carmel Capewell presented her photovoice research and found that many of her participants, rather than taking their own photos, had used the internet to search for images.

Another participant, allowed her friend to write a diary entry in her diary. Within this post they detailed how the participant had overcome obstacles placed in their way by PCOS. For example, she writes:

'Since I have known about PCOS I have seen a change in her. She knows exactly what she needs to do to jump over this hurdle. I am so proud of her because, I've heard of other cases and how them individuals cope. [They] have taken all the negatives, of this case and turned them into possible positives...It seems like yesterday that she told me, but it's been four years. Glad to say she has accepted the condition, but shes also ready to do something about it.'

It is evident then, that photovoice is still a 'new' method and future research should allow participants more creative freedom within the method, which could help to uncover original research findings. Photovoice could also be expanded to include family members and friends in order to explore their perceptions of the participant and their PCOS, or other phenomena.

8.7 Strengths and Limitations

There are a number of strengths and limitations to the research detailed in this thesis. Many of these are discussed at length within each chapter. However, there were also a number of strengths and limitations across the thesis including the use of online research methods.

There were several benefits to utilising online research methods; the most evident was the ability to recruit a large sample of participants from a disease-specific population (this is most evident in Chapter Five and Six). An additional benefit was the ability to recruit participants who were located throughout the UK rather than in a specific area (such as Derby or Derbyshire). Moreover, utilising online methods resulted in time and cost savings: reaching a sample size of 714 would have been unlikely if participants had been required to complete measures in a face-to-face scenario. This was similarly evidenced in Chapter Four as participants were unable to take part in face-to-face interviews or focus groups, opting instead to take part online.

It could also be considered a strength that the lead researcher was female as many of the PCOS groups on Facebook that were used for recruitment did not allow male members, even if that person had joined the group in order to support a loved one such as a wife or daughter. Often members of the group would express discomfort at the thought of a man being a member of the group and participating, or viewing, discussions between the female members of the group with PCOS. In addition, the lead researcher also had PCOS and so it is possible that being diagnosed with the condition, and sharing this information with participants when

asked, may have made the researcher more approachable and allowed the participants to feel more comfortable sharing, often emotive, information with them.

This self-disclosure, defined as ‘the act of revealing personal information to others’ (Archer, 1980, p.183), may have helped form a closer relationship with participants. Certainly, research suggests that when conducting email interviews, the researcher should introduce and provide information about themselves, as this may help the participants engage in self-disclosure (Meho, 2006; Moon, 2000). Joinson (2001) similarly found that participants were more open in their responses to internet based surveys when the researcher engaged in self-disclosure. Moon (2000) details the principal of self-disclosure reciprocity whereby a person is more likely to engage with self-disclosure, if the previous speaker has engaged in self-disclosure as well. Similarly, Derlaga and Berg (2013) suggest if a person self-discloses, the receiver is also likely to self-disclose. They also propose that self-disclosure may result in increased liking by the recipient for the self-discloser. In addition, Dindia and Allen (1992) found through a meta-analysis of 205 studies, that women were more likely to self-disclose to other women. This would support the above discussion that being a woman with PCOS made the researcher more approachable and encouraged participants to share their experiences. However, there is yet to be research which explores the impact of researcher gender on recruitment in Facebook groups or on possible negative consequences of self-disclosure in this setting. Future research is needed to explore the impact of the researcher’s gender on recruitment in predominantly female Facebook groups and the possible consequences for recruitment and the nature of the data collected due to self-disclosure on the part of the researcher.

Recruiting participants from Facebook support groups, however, may have meant that the population sample was biased as participants were already seeking support and therefore the findings of this thesis may not be applicable to those women with PCOS who are not seeking support online. Trepte and Reinecke (2013) suggest that individuals who use social networking sites like Facebook are more likely to engage in self-disclosure. As recruitment took place online for all studies, participants could only be excluded if they self-reported that they did not meet the inclusion criteria. For example, in Chapter Three (the photovoice study) participants were asked to confirm that they met the inclusion criteria and therefore did not experience any other long-term or psychological illness which was not related to the PCOS (Chapter Three, Section 3.3). Whilst most potential participants were open about whether

they met the criteria or not, it is possible that participants could have experienced other conditions, not disclosed this and consequently have taken part in the study.

Another strength of this thesis is the mixed-methods approach utilised (see Chapter Two for more detail). Use of a mixed-methods approach allowed for the participants' experiences to be explored and consequently enabled the quantitative studies to be derived from the experiences of women living with PCOS in the UK. Studies derived from previous literature, or from the researchers own assumptions, may not have adequately reflected the experience of women with PCOS. Moreover, the findings of the quantitative chapters led to other research questions which should be explored qualitatively in order to gain a deeper understanding of the phenomena. For example, in Chapter Four, self-harm was spontaneously discussed by participants. Consequently, in the quantitative studies participants were asked about their self-harm history, revealing high levels of a history of self-harm in the population. This resulted in the identification of the need for further qualitative research which explores how women with PCOS experience self-harm, continuing the research development process.

Creswell (2003) describes this process as sequential, whereby the researcher expands on findings of one method, with another method; an example being, beginning with qualitative methods for exploratory purposes and following up with quantitative methods to generalise results to a population. Furthermore, Creswell suggests that a mixed-methods approach employs strategies that involve collecting data sequentially to best understand research problems. Similarly, Denscombe (2008) suggests that mixed methods approaches have been previously used to allow for a more complete picture of the data to be produced and as a way of developing analysis and building on initial findings. Suggested future qualitative research derived from the quantitative aspects of this thesis; include an exploration of the impact of feminine identity on quality of life, and exploring perceived pressure to conceive in women with PCOS.

8.8 Recommendations for Clinical Practice

The findings from this thesis have a number of implications for clinical practice. One of the most important is for health care professionals to be aware that women with PCOS are likely to experience depression and anxiety and be prepared to offer appropriate support to these women. Moreover, this thesis revealed that women with PCOS may be unable to meet child-

related goals. As such, health care professionals working with women with PCOS who have been trying, but are unable to have children, should provide appropriate support to help them adjust their goals.

Findings from Chapter Three demonstrated that PCOS can be a changing condition which makes it difficult for women with PCOS to manage their symptoms over time. In addition, according to whether the woman wishes to try for children or not, the treatments they receive will also change. As such, health care professionals should be considerate that symptoms of PCOS, and the necessary treatments, will change over the lifespan. Women with PCOS should therefore be required to follow up with their health care professional on a regular basis in order to help them maintain control over their condition, or indeed, to change treatments when necessary.

In Chapters Three and Four participants discussed how they seek information and support from online sources including blogs such as Tumblr and social networking websites. Health care professionals should be aware of this and ensure that correct and up-to-date information regarding PCOS is available online from a recognised and trusted source, such as a GP practice or hospital website. Furthermore, online message boards which are moderated by a qualified health care professional could enable women with PCOS to feel more supported by the health care system, and ensure that these women have access to appropriate advice and information. One possibility is that a lay member of the public is employed as a moderator who would be able to guide group members to appropriate sources of information and advice made available through the relevant health care professionals, similar to Facebook group administrators. Greene et al. (2010) also suggest that policymakers should consider that patients may seek social networking websites developed and patrolled by health care professionals to promote accurate and unbiased information exchange.

Finally, Chapter Six identified that women with PCOS may be more likely to experience the symptom of skin tags than previously reported. As this symptom is part of Acanthosis Nigricans, a condition that can be an early sign of diabetes (NHS, 2013), health care professionals should carefully screen women that present with skin tags and skin discolouration and PCOS for diabetes.

8.9 Future Directions

There have been many recommendations for future research throughout this thesis. This section shall summarise the recommendations detailed within Chapters Three to Seven.

This thesis has provided some insight into the experience of women with PCOS but further qualitative research is necessary as there still remains a need for research which describes and interprets the personal experiences of women with PCOS (Smith, 2015). Qualitative research will facilitate rich descriptions and explanations of their world and how they make sense of their lives (Coyle, 2016). Specifically, there is a need for further qualitative research which utilises methods such as photovoice in order to explore the day-to-day experiences of women with PCOS in more depth, as defined by them and not at the request of the researcher. The use of this method in this thesis allowed participants to use photographs and diaries in novel ways which could be further explored in future research in order to help the researcher understand how women with PCOS make sense of their condition and the impact it has on their lives.

This thesis highlighted that women with PCOS use social media websites such as Tumblr and social networking websites like Facebook to gain information and support about their PCOS. As such, there is also a need for future research which explores how women with PCOS utilise online media to educate themselves about their condition and how they make use of online support from social networks such as Facebook and the impact this may have on them, both negative and positive. Qualitative methods would allow women with PCOS to share their experiences of using online media and social networking websites to gain information about their condition. Moreover, through using qualitative methods a further understanding of the role of social networking websites in social support could be gained. This would also further understanding of how women with PCOS gain knowledge about their condition, how they form relationships with other women with PCOS online, and also provide a deeper understanding of the role of support in these environments.

This thesis identified that women with PCOS felt under pressure to conceive (Chapter Three and Four). As such, further qualitative research would enable an in-depth exploration of this perceived pressure as experienced by women with PCOS. Moreover, qualitative research could investigate why women with PCOS perceive pressure to conceive, and where this pressure is perceived to be from. In addition, research should explore the impact of advice to

conceive earlier rather than later from health care professionals on women with PCOS and the impact this advice and/or pressure may have on younger women with PCOS who may not be in an appropriate position to have children (financial instability etc.). How health care professionals communicate with their patients with regards to family planning and the way this is understood by those patients should also be explored with both women with PCOS and the health care professionals who advise and communicate with them.

Women with PCOS can experience several physical and psychological co-morbid conditions in addition to their PCOS, as demonstrated in Chapter Four and Six. There is, therefore, a need for research which explores the prevalence of co-morbid conditions in women with PCOS and how these women experience and manage multiple conditions. Participants in Chapter Four also spontaneously discussed their experiences of self-harm and Chapter Six revealed that women with PCOS had high rates of self-harm when asked if they had a 'history of self-harm'. However, how the participant perceived and defined self-harm is not clear in this context. As such, further research is needed that explores the prevalence of self-harm in women with PCOS, how women with PCOS define self-harm, and their experiences with regards to self-harm.

Future research is also necessary to further validate the PCOSQOL in a clinical population and in women with PCOS who have differing lengths of diagnosis. Moreover, the PCOSQOL should be validated with participants in countries outside of the UK. This will enable the PCOSQOL to be used in clinical practice as a measure of quality of life in different countries. Further research exploring the associations between PCOS and symptoms experienced is necessary. In addition, future research should explore associations between PCOS and types of anxiety experienced by women with PCOS, particularly Social Anxiety Disorder and Panic Disorder. Research is also needed to explore the prevalence of Skin Tags in women with PCOS. Methods of coping used by women with PCOS would be useful to investigate, particularly the role of optimism in coping and adjustment in women with PCOS and coping strategies used by women who are presently involved in the health care system and those who have been discharged.

Finally, this thesis revealed that being a part of a positive psychology intervention may have a positive impact on quality of life for women with PCOS regardless of the condition they are assigned to (intervention/control). However, this intervention was underpowered; therefore,

future research should explore the impact of a positive psychology intervention in a large sample of women in order to ensure that the study is appropriately powered. Future research utilising a positive psychology intervention should seek to complete a minimum of a single-blinded randomised controlled trial, and also provide participants in the control group with a placebo activity.

8.10 Reflection

This section discusses some personal reflections on this thesis and the journey completing it. Jasper (2005) states that reflective writing “acknowledges at the outset that what is presented is that relating and purporting to the experiences and perceptions of the author” (p.250). As such, this section will be written in first person.

As detailed in Chapter Two of this thesis, I had previously been diagnosed with PCOS. As has been stated several times in this thesis, PCOS can impact each individual differently and my experience of PCOS is at the mild end of the spectrum, with a symptom profile that pertains mostly to insulin resistance. It was my early diagnosis that led me to complete a qualitative analysis of discussion boards used by women with PCOS for my undergraduate dissertation: this study later formed the basis of my PhD proposal.

During recruitment for these studies I did not disclose my diagnosis to participants. However, if participants asked why I was doing the research I explained that my interest had developed from earlier personal experiences, this seemed to help develop my rapport with potential participants and members of the Facebook support groups. In addition to participants asking about my interest, I have also been asked by other academics and researchers; why did you chose this topic? And, does this have an impact on your research? Consequently, I have had time to reflect on my position and whilst I do believe that my position has allowed me to be empathetic to my participants, as my experiences differ from those of my participants, my analyses were able to remain grounded in the data and not my personal experiences.

Moreover, I attempted to ensure that my analyses represented the data by discussing it with my supervisory team, particularly in the qualitative studies (Chapter Three and Four) when discussing themes (Yardley, 2015).

Whilst there were aspects of completing my PhD that were difficult; these pertained to the emotive nature of the research, rather than my own experiences. Certainly, the most

surprising finding to me was the voluntary discussion of self-harm in Chapter Four, and the subsequent figures of ‘a history of self-harm’ and diagnoses of depression and anxiety in Chapter Six. However, whilst these findings were emotive, I was able to discuss them within my supervision team, and in my wider support network.

Another emotive aspect of this research came through recruitment: the only ‘down-side’ of recruiting through the Facebook groups was receiving a constant stream of posts on my own personal Facebook, as a result of belonging to the group. These were often highly negative and/or highly emotive posts: the worst of which included photos of miscarried foetuses and babies. Other posts were often labelled as TMI (too much information) and included photographs of menstruation or other bodily fluids. At times I did find these posts rather distressing and I found that the negativity of the posts was beginning to have an impact on my own mood. So, after recruiting for the scale development study I removed myself from many of these groups and attempted to limit the posts I could see from the ones I stayed in, re-joining only to recruit for the intervention study. In this way, online recruitment and data collection differs from face-to-face scenarios. In a face-to-face situation you would recruit your participant, generate and collect data, and then you would then no longer be a part of that participant’s personal life: you play the role of researcher and participant. When recruiting on Facebook, by using a personal Facebook profile, the (potential) participants’ lives become embedded within the researcher’s, so your personal time becomes saturated with the personal lives and troubles of the population, and it becomes difficult to remove oneself from the scenario.

Chapters Three and Four demonstrated that women with PCOS were seeking support from online social networking sites such as Facebook. It may be, therefore, that this overload of negativity may have a similar impact on the women in the groups, particularly as they were often members of several Facebook groups. Indeed, Weiss and Bulmer (2011) reported that participants in their study did not find satisfaction in using dedicated PCOS support groups. Furthermore, Malik and Coulson (2010) report that of 295 women using dedicated online support forums for infertility over 57% reported disadvantages to online support including reading about negative experiences. In addition, Holbrey and Coulson (2013) found that women with PCOS reported negative aspects of using dedicated online support forums, including reading about the negative experiences of other members. It remains, however, that dedicated online support groups are often held on external websites outside of the

individual's personal Facebook page. Future research should, therefore, explore the function of Facebook support groups for the women who are part of them.

At the 12th Annual Psychology, Health and Medicine conference in Belfast, Northern Ireland (2015), Trish Niland described a study which explored how young adults airbrushed drinking practices on Facebook. In their study participants accessed their Facebook pages and discussed their profiles with the researcher to explore how young adults made use of Facebook. Bender, Jimenez-Marroquin and Jadad (2011) conducted a content analysis on Facebook support groups for women with breast cancer. They suggest that Facebook groups are a popular tool for support-seeking and raising awareness, but that further research is necessary to explore the implications of social networking sites as a health resource. In addition, Greene, Choudhry, Kilabuk and Shrank (2010) conducted a qualitative analysis of Diabetes management groups on Facebook. They found that Facebook provided a forum for reporting personal experiences, and gaining feedback from individuals living with diabetes. Therefore future research is needed that explores how women with PCOS use Facebook and other online media to gain support and the role it plays for them.

8.11 Conclusion

In 2012 the Amsterdam ESHRE/ASRM- sponsored 3rd PCOS consensus workshop group summarised current knowledge regarding PCOS and published their recommendations for future research to fill the various knowledge gaps regarding women's health in PCOS. With regards to quality of life, the workshop group recognised that there is a need for the prevalence of psychological disorders in women with PCOS to be determined, and that there is a need for appropriate interventions to be developed. Moreover, the workshop group claimed that studies in the area of quality of life were hampered by the existence of only one disease specific quality of life questionnaire for women with PCOS (The PCOSQ: Cronin et al. 1998). As such, this PhD has addressed many of the concerns and recommendations of the workshop group through: development and validation of a UK disease specific quality of life scale (PCOSQOL), exploration of the prevalence of anxiety and depression in a large sample of women with PCOS and the development and piloting of an online positive psychology intervention.

The findings of this thesis suggest that PCOS has a negative impact on quality of life: they demonstrate that quality of life for women with PCOS is reflective of psychological,

physical, social, environmental, independence and spiritual/religion/personal belief domains as previously reported by the WHOQOL Group (1994). However, the findings of this thesis suggest that for women with PCOS the majority of quality of life concerns fall within the psychological, physical and social domains of quality of life (Fayers & Machin, 2007; Testa & Simonson, 1996). The findings also suggest that quality of life for women with PCOS is associated with the experience of specific symptoms, including: infertility, obesity, alopecia, skin discolouration, skin tags and mood swings. In addition, living with co-morbidities, particularly psychological co-morbidities, may be important aspects of quality of life for women with PCOS. Whilst this thesis has furthered understanding of the impact of PCOS on quality of life for women with the condition in the UK, and attempted to improve quality of life; there remains a need for research which explores further the quality of life in women with PCOS and how to improve it.

Chapter Nine -References

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Chapter Ten - Appendices

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Appendix A: Photovoice study – invite to participate

PCOS and the impact on quality of life

If you are over 18, live in the UK and suffer from PCOS and you would like to take part in a PhD study researching the impact of PCOS on quality of life then please email S.Williams3@derby.ac.uk. The study has been granted ethical approval from the University of Derby and will abide by the British Psychological Society's ethical guidelines. You will remain anonymous and all information will be confidential. All you would need to do for the study is take photographs (camera provided) and write diary entries (notepad provided) for one week of anything you which you feel relates to your quality of life and PCOS. There are no right or wrong answers. If you are interested please just email me on the address above and I can send you out some information - you are not obliged to participate.

Appendix B: Photovoice study – consent form

Polycystic Ovary Syndrome on quality of life through the use of a photovoice methodology.

Researcher – s.williams3@derby.ac.uk
Director of Studies – r.c.knibb@derby.ac.uk
University of Derby

Thank you for your interest in taking part in this research. This research is being undertaken as part of a postgraduate research degree. This research has been granted ethical approval by the University of Derby Psychology Research Ethics Committee. This research will require you to take photographs on a disposable camera and to make a diary entry in the notebook provided explaining each photograph you take.

Anonymous verbatim quotes from the diary entries will be used as part of the research findings in the final written report and possibly in publications, I guarantee that all identifying details will remain anonymous, being seen only by the researcher and research supervisors of this study. There will be no reference to names or any identifying details of the participants. Your decision to participate is completely voluntary and you may withdraw from this research at any point up to three weeks after participation, you do not need to give a reason or explanation for doing so.

You will also be required to create a unique participant code. This is a code made up of three items of any combination, of letters or numbers. This code must be easy for you to remember as it will enable you to withdraw your research easily if you so chose too. If you have any questions about the research, please feel free to ask the researcher before you decide whether you want to take part.

Participants Statement of Informed Consent

- I understand that I have agreed to participate in a photovoice study which will require me to take photographs and make diary entries for a period of one week.
- I understand that if, at any time, up to three weeks, I decide I no longer wish to take part in this project, I can notify the researcher involved and withdraw immediately.
- I agree that the research project named above has been explained to me to my satisfaction and I have had the opportunity to ask the researcher any questions.
- I understand that anonymous verbatim quotes may be used in the final report and may be published.
- I understand that anonymity will be maintained and it will not be possible to identify me.
- I understand that any photographs containing people, without their verbal consent, shall be destroyed and shall not be republished.

I have read and understand the above statements and agree to take part in this study:

Appendix C: Photovoice study – letter of instructions

Sophie Williams
Centre for Psychological Research
Faculty of Education, Health and Sciences
University of Derby
Kedleston Road
Derby
DE22 1GB
S.Williams3@derby.ac.uk

Dear Participant,

I would like to thank you for your interest and participation in this research study. Please be reminded that to take part in this study you need to be a woman with PCOS, aged 18 years and above and have no other chronic or mental illness (which is not related to PCOS). Everything you need should be found inside the envelope you received along with this letter. This includes a disposable camera, a notepad, an information pack, a consent form and a return envelope with a pre addressed sticker. If you do not have any of those things please contact me and I will get them to you straight away. Also, the information sheet is yours to keep should you have any questions during or after participation in this research.

In your study pack you should find a consent form as mentioned before. It is important that you read the information sheet (contacting me or the research team with any questions – details found in the information sheet) and then sign the consent form and return it with your camera and notepad once you have finished taking part in the study. If we do not receive a signed consent form then we cannot use your data in the research.

To take part in this study all you need to do is take photographs of anything which you feel is related to your PCOS and has an impact on your quality of life. This could be something that enhances your quality of life or makes it worse (there are no good or bad photographs). For each photograph you take please make a diary entry in the notepad about the photograph, for example, what it is of (if it is unclear) or why you decided to take it. Again, there are no right or wrong ‘answers’ here.

You are asked to do this (take photos and make diary entries) over a period of one week. Should you use all your camera exposures before the week is over please feel free to return the study pack early (excluding your information sheet). Don’t worry if a week finishes and you have not used all your exposures, just send the camera and notepad back with whatever you have done.

To send your camera, notepad and consent form back just place the pre addressed sticker on the front of the envelope you received and post it back to us.

We also ask that, should you wish to take photographs of any people, that you gain their consent first (more information about this is available in the information sheet). We also ask that you do not take any inappropriate images for example, featuring nudity.

If you have any questions please feel free to contact myself or the research team on the contact details above (and in the information sheet).

Once again thank you for your participation,

Many thanks

Sophie Williams

Appendix D: Photovoice study – information sheet

Sophie Williams
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Faculty of Education, Health and Sciences
University of Derby
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Director of Studies
Dr Rebecca Knibb
r.c.knibb@derby.ac.uk

A qualitative exploration of the impact of Polycystic Ovary Syndrome on quality of life: Information Sheet

My name is Sophie Williams and I am a postgraduate research student at the University of Derby. I am currently researching Polycystic Ovary Syndrome and its impact on quality of life. I am inviting you to take part in a study which will form one part of my PhD.

Before you decide if you would like to take part, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully. If anything is not clear and you would like some more information you can get in touch with me on the above number or email address. Please take your time to decide whether or not you wish to take part.

Thank you for reading this.

The purpose of the study:

To date there has been no research exploring the impact of PCOS on quality of life using visual data (photographs or drawings etc). This research hopes to fill this gap in the academic literature and therefore, further understanding of the experience of PCOS and its impact upon an individual's quality of life.

Why have I been chosen to take part?

You will have been selected to take part if you are a woman with PCOS, who has no other chronic or mental illness not related to PCOS and who is over 18 years of age.

Do I have to take part?

No, it is up to you to decide whether or not to take part. If you decide to take part you will be asked to keep this information sheet and to sign a consent form, which says you are happy to take part. If you decide to take part you are free to withdraw (stop taking part in the study) at any time up to three weeks after taking part and without giving a reason. If you do take part

in the study and you change your mind afterwards, you can just contact us and we will destroy all the information and photographs you gave us.

To do this you will need to have a unique participant code which is a code made up of three items (numbers or letters) which you create. Make sure you keep a copy of this code (we suggest writing it on the information sheet which you will keep). Please write the code clearly on the provided notepad, this way the researcher can easily recognise and withdraw your data.

What does taking part involve?

You will be asked to take photographs on a provided disposable camera for one week which relate to the impact of PCOS on your quality of life. These may be photographs of something which enhances your quality of life or makes it worse (there are no good or bad photographs). For each photograph you take please make a diary entry in the notepad provided about the photograph, for example, what it is of (if it is unclear) or why you decided to take it or even how you were feeling at the time. Again there is no right or wrong 'answer' here.

When the week is up, or when you have used all of your camera exposures you will then be asked to put the camera and the notepad along with your consent form in an envelope and to mail it back to the researcher and research team.

If you decide to take part in this study a study pack (containing a copy of the information sheet, a consent form, instructions for participant, a disposable camera, notebook and pen) will be sent to you.

What should I take photographs of?

You can take photographs of absolutely anything you feel impacts on your quality of life, be it positively or negatively. There is no limit to this and no right or wrong answer.

We only ask that should you wish to take photographs of people you gain their consent. Although photographs of people will not be published or used for any other purpose than the psychological analysis for this study and my PhD thesis; it is still necessary that the person you wish to photograph is aware that it will be seen by me and the research team. It is also important that the individual understands the photograph is being taken for a PhD study. Therefore fully informed verbal consent should be gained from anyone you may wish to photograph.

We also ask that you refrain from taking any inappropriate images, for example photos containing nudity.

What are the benefits of taking part?

By taking part you will be helping to further understanding of PCOS.

What are the disadvantages of taking part?

There are no disadvantages to taking part in this study.

What if there is a problem?

If you have any concerns or complaints about anything to do with this study, please speak to the researcher or research team and we will do our best to answer your questions. You can email Sophie Williams (email address is at the top of this information sheet) or Dr Rebecca Knibb (email address and phone number at top of this information sheet). If you are still unhappy and want to complain formally, you can do this through the University of Derby's procedures by contacting the head of the School of Science Dr Mike Gillespie on m.gillespie@derby.ac.uk.

Will the information I give in this study be kept confidential?

Yes, all information collected from you for this study will be kept strictly confidential. That means that no one outside of the research team will see any of the information you give us. Each person taking part in the study will be given a unique participant code that we will use when looking at what you have written in the notebooks and the photographs you have taken.

Anonymised verbatim quotes from the diary entries will be used as part of the research findings in the final written report. Information will be kept in a locked filing cabinet and on a password protected computer at the University of Derby for up to 7 years and then it will be destroyed.

What will happen to the results of the study?

The information you give us will be analysed by Sophie Williams and the research team. The finding of this study will be written up into a report; this will form part of the PhD and may be published and presented at conferences etc. We can send you a copy of the report if you would like it. Your name will not be included in the report nor will any photographs of people be published in any publications.

Who has reviewed the study?

This study has been looked by the Ethics Committee at the University of Derby and is in accordance with the ethical guidelines of the British Psychological Society. These are a professional body of psychologists in the UK who check research to make sure that it protects the safety, rights, wellbeing and dignity of anyone who takes part.

Can I get more information?

If you are interested in taking part in this study but would like some more information before you decide, please talk to Sophie Williams or contact Dr Rebecca Knibb (contact details provided above). If you would like to talk to someone about research in Psychology at the

University please contact the Head of the Centre for Psychological Research, Professor James Elander, on j.elanders@derby.ac.uk.

If I decide to take part what do I do now?

If you do decide to take part in this study, thank you very much. Please keep a copy of this information sheet.

Thank you for taking the time to read this information sheet.

Yours sincerely

Sophie Williams
Postgraduate Student

Research Team:

Dr Rebecca Knibb (director of studies), Prof. David Sheffield, Dr Heidi Sowter.

Appendix E: Photovoice study – PREC approval letter (050-11-SW)

Approval Letter: Psychology Research Ethics Committee

University of Derby

6th February 2012

James Elander

Chair, Psychology Research Ethics Committee, University of Derby

Dear Sophie,

Ethics Ref No: 050-11-SW: A qualitative exploration of the impact of Polycystic Ovary Syndrome on quality of life.

Thank you for submitting this revised application to the Psychology Research Ethics Committee.

The reviewers of your original application have now reviewed the revised documents you sent following the feedback you received on your initial application, and are all satisfied that all of the issues raised have been dealt with. The application can now therefore be approved.

The following documents have now been reviewed:

1. Revised ethics application form
2. Revised letters to participants
3. Revised participant information forms
4. Revised consent form
5. Debriefing information

If any changes to the study described in the application or supporting documentation is necessary, you must notify the committee and may be required to make a resubmission of the application.

Good luck with the study.

Yours sincerely

James Elander

Appendix F: Skype study – invite to participate

Participants required to take part in research concerning “The impact of PCOS on quality of life”; a study being run by a PhD student at the University of Derby, UK. Your participation will remain confidential and anonymous and is completely voluntary. You may also withdraw from the research after participation.

There are two parts to this study: you can choose to take part in either:

- (1) (a) Participation will involve you taking part in a focus group with up to 6 other women with PCOS and may last up to two hours. The focus group will take place at the University of Derby.

(b) If you have taken part in the focus group you will also be invited to participate in a face to face or online interview which may last between one and two hours. The interview will take place at the University of Derby, UK or an alternative safe location may be arranged.
- (2) Participation will involve you reviewing a document of statements related to PCOS. This may be via the postal system (all postage costs will be provided) or via email.

To take part you must meet the following criteria: have a diagnosis of PCOS, be 18 or over, live in England and have English as a first language. Participants must not suffer from any other condition which is unrelated to PCOS.

If you are interested in either study please contact S.Williams3@derby.ac.uk or call 01332592019 for more information. There is no obligation to participate.

Appendix G: Skype study – information sheet

Sophie Williams
Centre for Psychological Research
Faculty of Education, Health and Sciences
University of Derby
Kedleston Road
DE22 1GB
S.Williams3@derby.ac.uk

Director of Studies
Dr Rebecca Knibb
r.c.knibb@derby.ac.uk

A qualitative exploration of the impact of Polycystic Ovary Syndrome on quality of life: Information Sheet

My name is Sophie Williams and I am a postgraduate research student at the University of Derby. I am currently researching Polycystic Ovary Syndrome and its impact on quality of life. I am inviting you to take part in a study which will form one part of my PhD.

Before you decide if you would like to take part, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully. If anything is not clear and you would like some more information you can get in touch with me on the above number or email address. Please take your time to decide whether or not you wish to take part.

Thank you for reading this.

The purpose of the study:

Why have I been chosen to take part?

You will have been selected to take part if you are a woman with PCOS, who has no other chronic or mental illness not related to PCOS and who is over 18 years of age, who also lives in England and has English as a first language.

Do I have to take part?

No, it is up to you to decide whether or not to take part. If you decide to take part you will be asked to keep this information sheet and to sign a consent form, which says you are happy to take part. If you decide to take part you are free to withdraw (stop taking part in the study) at any time up to three weeks after taking part and without giving a reason. If you do take part in the study and you change your mind afterwards, you can just contact us and we will destroy all the information you gave us and your data.

To do this you will need to have a unique participant code which is a code made up of three items (numbers or letters) which you create. Make sure you keep a copy of this code (we suggest writing it on the information sheet which you will keep). You will be asked to

provide the code either during the online interview or you will be asked to write it on a demographic information sheet, this way the researcher can easily recognise and withdraw your data.

What does taking part involve?

There are three parts to this study: you can choose to take part in all or just one part:

- (3) Participation will involve you taking part in a focus group with up to 6 other women with PCOS and may last up to two hours. The focus group will take place at the University of Derby.
- (4) If you have taken part in the focus group you will also be invited to participate in a face to face or online interview which may last between one and two hours. The interview will take place at the University of Derby, UK or an alternative safe location may be arranged.
- (5) Participation will involve you reviewing a document of statements related to PCOS. This may be via the postal system (all postage costs will be provided) or via email.

What are the benefits of taking part?

By taking part you will be helping to further understanding of PCOS.

What are the disadvantages of taking part?

There are no disadvantages to taking part in this study.

What if there is a problem?

If you have any concerns or complaints about anything to do with this study, please speak to the researcher or research team and we will do our best to answer your questions. You can email me (Sophie Williams, my email address is at the top of this information sheet) or Dr Rebecca Knibb (email address and phone number at top of this information sheet). If you are still unhappy and want to complain formally, you can do this through the University of Derby's procedures by contacting the head of the School of Science Dr Mike Gillespie on m.gillespie@derby.ac.uk.

Will the information I give in this study be kept confidential?

Yes, all information collected from you for this study will be kept strictly confidential. That means that no one outside of the research team will see any of the information you give us. Each person taking part in the study will be given a unique participant code that we will use when looking at what your data from interviews and focus groups.

Anonymised verbatim quotes from the interview or focus group will be used as part of the research findings in the final written report and may be published. Information will be kept in a locked filing cabinet and on a password protected computer at the University of Derby for up to 7 years and then it will be destroyed.

What will happen to the results of the study?

The information you give us will be analysed by Sophie Williams and the research team. The finding of this study will be written up into a report; this will form part of the PhD and may be published and presented at conferences etc. We can send you a copy of the report if you would like it. Your name will not be included in the report nor will it be published.

Who has reviewed the study?

This study has been looked by the Ethics Committee at the University of Derby and is in accordance with the ethical guidelines of the British Psychological Society. These are a professional body of psychologists in the UK who check research to make sure that it protects the safety, rights, wellbeing and dignity of anyone who takes part.

Can I get more information?

If you are interested in taking part in this study but would like some more information before you decide, please talk to me (Sophie Williams) or contact Dr Rebecca Knibb (contact details provided above). If you would like to talk to someone about research in Psychology at the University please contact the Head of the Centre for Psychological Research, Professor James Elander, on j.eland@derby.ac.uk.

If I decide to take part what do I do now?

If you do decide to take part in this study, thank you very much. All you need to do is let me (Sophie Williams) know you wish to take part and I will guide you through the rest of the process. Please also keep a copy of this information sheet.

Thank you for taking the time to read this information sheet.

Yours sincerely

Sophie Williams
Postgraduate Student

Research Team:
Dr Rebecca Knibb (director of studies), Prof. David Sheffield, Dr Heidi Sowter.

Appendix H: Skype study – consent form

The Impact of Polycystic Ovary Syndrome on Quality of Life

Researcher – s.williams3@derby.ac.uk

Director of Studies – r.c.knibb@derby.ac.uk

University of Derby

Thank you for your interest in taking part in this research. This research is being undertaken as part of a postgraduate research degree. This research has been granted ethical approval by the University of Derby Psychology Research Ethics Committee. This research will require you to take part in a face to face or online interview with the primary researcher on in a focus group

Anonymous verbatim quotes from the interviews and focus groups will be used as part of the research findings in the final written report and possibly in publications, I guarantee that all identifying details will remain anonymous, being seen only by the researcher and research supervisors of this study. There will be no reference to names or any identifying details of the participants. Your decision to participate is completely voluntary and you may withdraw from this research at any point up to three weeks after participation, you do not need to give a reason or explanation for doing so.

You will also be required to create a unique participant code. This is a code made up of three items of any combination, of letters or numbers. This code must be easy for you to remember as it will enable you to withdraw your research easily if you so chose too. If you have any questions about the research, please feel free to ask the researcher before you decide whether you want to take part.

You will also be asked to provide your contact details. This is so the researcher can contact you with any vital information (for example, informing you of changes to interview or focus group times) or to give you reminders (for example, about an upcoming interview).

Participants Statement of Informed Consent

- I understand that I have agreed to participate in a face to face or online interview or in a focus group.
- I understand that if; at any time up to three weeks, I decide I no longer wish to take part in this project, I can notify the researcher involved and withdraw immediately.
- I agree that the research project named above has been explained to me to my satisfaction and I have had the opportunity to ask the researcher any questions.
- I understand that anonymous verbatim quotes may be used in the final report and may be published.
- I understand that anonymity will be maintained and it will not be possible to identify me.
- I understand that the researcher may contact me via email or telephone when necessary throughout the research process.

I have read and understand the above statements and agree to take part in this study.

Participant signature:

Appendix I: Skype study – interview schedule

Please could you tell me how you first became aware of your PCOS?

- What did you think about it?
- How did you feel about it?
- Can you tell me more about that?
- Do you have any examples?

Could you describe a typical day for you living with PCOS?

- How did you/do you feel about that?
- Can you tell me more about that?
- Do you have any examples?

Do you think PCOS has changed the pattern of your life at all?

- Did/do you make any major changes?
- How did/do you feel about this?
- What did/do you think about this?

Have you changed the way you deal with your PCOS and its symptoms over time?

- In what ways?
- Does anything, any situation make it better?
- Does anything, any situation make it worse?
- How do you feel about these changes?

Can you describe how having PCOS effects your relationships with others?

- Family and friends
- Doctor
- University Lecturers/Colleagues

Has having PCOS changed the way you think or feel about yourself?

- Do you see yourself differently now than before being diagnosed with PCOS?
- Do you think others see you differently?

If you suffer from any other type of illness or disorder, how do you manage this?

- In what ways?
- Does anything, any situation make it better?
- Does anything, any situation make it worse?

Could you please look at this questionnaire and tell me your thoughts on it? *This questionnaire refers to the PCOSQ (Cronin et al., 1998).*

Appendix J: Skype study – debrief

Sophie Williams
Centre for Psychological Research
Faculty of Education, Health and Sciences
University of Derby
Kedleston Road
Derby
DE22 1GB
S.Williams3@derby.ac.uk

Dear Participant,

Thank you very much for taking part in this research study. Your decision to participate is completely voluntary. Should you wish to withdraw from the research you may do so at any point, up to three weeks after participation. You will not need to give any reason or explanation for doing so. To withdraw your data simply contact the researcher or research team with your unique participant code (the three item code made up of numbers or letters).

Should you have any questions about the research please feel free to contact me on the above details. If you have lost your participant information sheet and would like another one please let me know and I will send you one.

If you would like more information about PCOS or have any worries about PCOS please contact your GP or visit www.verity-pcos.org.uk.

Many thanks

Sophie Williams

Appendix K: Skype study – PREC approval letter (06012-SW)

Approval Letter: Psychology Research Ethics Committee

University of Derby

2nd October 2012

James Elander

Acting Chair, Psychology Research Ethics Committee, University of Derby

Dear Sophie,

Ethics Ref No: 06012-SW: Exploring the impact of PCOS

Thank you for submitting this revised application to the Psychology Research Ethics Committee.

I have now reviewed the revised documents you sent following the feedback you received on your initial application, and I am satisfied that all of the issues raised have been dealt with. The application can now therefore be approved.

The following revised documents have now been reviewed:

1. Revised ethics application form
2. Revised invitation letters
3. Consent form

If any changes to the study described in the application or supporting documentation is necessary, you must notify the committee and may be required to make a resubmission of the application.

Good luck with the study.

Yours sincerely

James Elander

Appendix L: Scale development – The Polycystic Ovary Syndrome Questionnaire (PCOSQ)

Presented are sample items from the PCOSQ

Extract of Instructions:

For each question, you have seven rating options. Option 1 represents the greatest possible impairment, while Option 7 represents the least impairment. Choose only one option for each question. There is no right or wrong answer. Just choose the option that is closest to how you feel.

How much of the time during the last two weeks did you:

All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	Hardly any of the time	None of the time
----------------------------	-----------------------------	---------------------------------------	-----------------------------	-------------------------------------	---------------------------------------	-----------------------------

Feel like
you are not
sexy
because of
being
overweight?

Have
difficulties
staying at
your idea
weight?

During the past two weeks, how much of the time have you felt:

All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	Hardly any of the time	None of the time
----------------------------	-----------------------------	---------------------------------------	-----------------------------	-------------------------------------	---------------------------------------	-----------------------------

Concerned
with

infertility
problems?

Moody as
a result of
having
PCOS

Appendix M: The PCOS QOL Prototype

The Polycystic Ovary Syndrome Quality of Life Scale (PCOS QOL)

Instructions

This scale has been specifically designed to measure quality of life for women with Polycystic Ovary Syndrome (PCOS). Throughout this scale Polycystic Ovary Syndrome will be referred to as PCOS. The questions in this scale are concerned with your PCOS, your health and health related issues. Please respond to every question by selecting/highlighting the option that reflects how you feel the most. There are no right or wrong answers, just choose the answer that shows you feel best. Please choose only one answer for each question.

After reading each statement please circle the answer which you feel most applies to you. Please only circle one.

	Usually	Often	Sometimes	Occasionally	Rarely	Not At All	Does Not Apply
During the last four weeks how often have you:	1	2	3	4	5	6	7
Felt under pressure to lose weight	1	2	3	4	5	6	7
Felt under pressure to have a child	1	2	3	4	5	6	7

Felt guilty for being overly aggressive towards a friend or family member

1	2	3	4	5	6	7
---	---	---	---	---	---	---

Over reacted to day to day occurrence because of PCOS

1	2	3	4	5	6	7
---	---	---	---	---	---	---

Felt like you weren't a real woman because of your PCOS

1	2	3	4	5	6	7
---	---	---	---	---	---	---

Been unsatisfied with the support you receive from health care professionals

1	2	3	4	5	6	7
---	---	---	---	---	---	---

Felt down because of your PCOS

1	2	3	4	5	6	7
---	---	---	---	---	---	---

	1	2	3	4	5	6	7
--	---	---	---	---	---	---	---

Felt overwhelmed by your PCOS and depression

Felt unable to work because of your PCOS	1	2	3	4	5	6	7
Felt depressed about how PCOS has impacted my life	1	2	3	4	5	6	7
Had negative thoughts about your weight	1	2	3	4	5	6	7
Been worried about other people seeing your facial hair	1	2	3	4	5	6	7
Felt anxious about conceiving a child	1	2	3	4	5	6	7
Felt extremely tired	1	2	3	4	5	6	7
Felt depressed over difficulties conceiving a child	1	2	3	4	5	6	7

Felt like you were broken because of your PCOS

1	2	3	4	5	6	7
---	---	---	---	---	---	---

Felt a lack of intimacy in your relationships because of PCOS

1	2	3	4	5	6	7
---	---	---	---	---	---	---

Felt anxious about how you look

1	2	3	4	5	6	7
---	---	---	---	---	---	---

Been in pain because of your menstruation

1	2	3	4	5	6	7
---	---	---	---	---	---	---

Felt like less of a woman because of having PCOS

1	2	3	4	5	6	7
---	---	---	---	---	---	---

Felt self conscious because of my thinning hair

1	2	3	4	5	6	7
---	---	---	---	---	---	---

Had a short temper with my close friends and/or family	1	2	3	4	5	6	7
Felt like crying for no reason	1	2	3	4	5	6	7
Felt in control of my depression	1	2	3	4	5	6	7
Struggled to keep my weight stable	1	2	3	4	5	6	7
Struggled to keep to a specific diet	1	2	3	4	5	6	7
Felt depressed	1	2	3	4	5	6	7
Had trouble sleeping	1	2	3	4	5	6	7
Felt tired all the time	1	2	3	4	5	6	7

Felt abnormal because of my PCOS

1	2	3	4	5	6	7
---	---	---	---	---	---	---

Felt like I don't know what to do to help myself

1	2	3	4	5	6	7
---	---	---	---	---	---	---

Felt like I don't know what to do to control my PCOS

1	2	3	4	5	6	7
---	---	---	---	---	---	---

Felt frustrated with the health care I am receiving

1	2	3	4	5	6	7
---	---	---	---	---	---	---

Felt like I hated myself

1	2	3	4	5	6	7
---	---	---	---	---	---	---

Felt like my PCOS is in control of my life

1	2	3	4	5	6	7
---	---	---	---	---	---	---

Felt embarrassed about the way I look	1	2	3	4	5	6	7
Had problems in my relationships because of my PCOS	1	2	3	4	5	6	7
Felt moody because of my excess hair	1	2	3	4	5	6	7
Felt depressed because of the spots on my face	1	2	3	4	5	6	7
Felt depressed because of my hirsutism	1	2	3	4	5	6	7
Felt depressed because of my facial hair	1	2	3	4	5	6	7
Felt depressed because of my infertility	1	2	3	4	5	6	7

Found it hard to cope with my PCOS symptoms and my depression

1	2	3	4	5	6	7
---	---	---	---	---	---	---

Spent a lot of time and energy removing excess hair

1	2	3	4	5	6	7
---	---	---	---	---	---	---

Felt depressed over my struggle to have children

1	2	3	4	5	6	7
---	---	---	---	---	---	---

Felt angry that I have PCOS

1	2	3	4	5	6	7
---	---	---	---	---	---	---

Been envious of women without PCOS

1	2	3	4	5	6	7
---	---	---	---	---	---	---

Felt embarrassed about having PCOS

1	2	3	4	5	6	7
---	---	---	---	---	---	---

Felt embarrassed by my facial hair

1	2	3	4	5	6	7
---	---	---	---	---	---	---

Felt like a failure because of my trouble conceiving

1	2	3	4	5	6	7
---	---	---	---	---	---	---

Been frustrated by my irregular periods

1	2	3	4	5	6	7
---	---	---	---	---	---	---

Been upset by my irregular periods

1	2	3	4	5	6	7
---	---	---	---	---	---	---

Felt that it is unfair that I have PCOS

1	2	3	4	5	6	7
---	---	---	---	---	---	---

Lacked sexual intimacy with my partner

1	2	3	4	5	6	7
---	---	---	---	---	---	---

Struggled to cope with my PCOS and my other condition/s

1	2	3	4	5	6	7
---	---	---	---	---	---	---

1			4	5		
---	--	--	---	---	--	--

Been scared that you may not have children		2	3			6	7
--	--	---	---	--	--	---	---

Been worried about how your PCOS may change in the future	1	2	3	4	5	6	7
---	---	---	---	---	---	---	---

Self harmed because I felt depressed about my PCOS	1	2	3	4	5	6	7
--	---	---	---	---	---	---	---

Appendix N: Scale development – invite to participate

Hello,

I am looking for Participants to take part in some research to develop a quality of life questionnaire for women with Polycystic Ovary Syndrome (PCOS). This research will help form part of my PhD at the University of Derby. My PhD explores the impact of PCOS on quality of life. All you would have to do is answer some questions about your PCOS and some other questions to check if the new questionnaire works. Your participation will remain confidential and anonymous and is completely voluntary. You may also withdraw from the research after participation.

To take part you must meet the following criteria: have a diagnosis of PCOS, be 18 or over, live in the UK and have English as a first language. To read more information about the study just click on the link below, if you then decide you want to take part just continue on to the questionnaires.

PLEASE NOTE: Only take part in this study if you have not previously taken part in it – thank you.

This study has been granted ethical approval by the University of Derby Psychology Ethics Committee. If you have any questions please contact S.Williams3@derby.ac.uk or call 01332592898 for more information. There is no obligation to participate but we are grateful if you decide to participate – thanks.

Appendix O: Scale development – information sheet

Testing a Quality of Life Scale

Participant Information Sheet

Introduction

You are invited to take part in a research study to help develop and test a scale to measure quality of life for women with PCOS.

Who is doing this research?

The research is being undertaken by a team from The University of Derby and will form part of a PhD thesis. The research team includes Sophie Williams, a PhD student at the University of Derby; Professor David Sheffield, Assistant head of Psychological Centre for Research, Dr Rebecca Knibb, Senior Lecturer in Health Psychology at Aston University and Dr Heidi Sowter, Senior Lecturer in Biology at the University of Derby.

Why have you been invited to participate?

You have been invited to take part in this research as you have PCOS, live in the UK, can understand and read English and are over the age of 18.

What does taking part in this research involve?

The aim of the research is to develop and test a scale which will measure the quality of life in women with PCOS.

If you decided to participate all you will need to do is click the website link which will take you to a website where you can give consent to take part in this research. At this point you will be asked if you would be willing to participate in what we call a re-test, meaning that you would complete the questionnaires again at a later date.

Once you have given consent you will be asked to fill out some general information such as age and diagnostic information. You will then be able to complete the questions on the quality of life scale as well as some other questions taken from other psychological scales (we use the other scales to help check the new one is right). If you decide not to take part in the re-test you will not be required to do anything else. You will then see, on the website, what we call a debrief which summaries the study you have just taken part in. If you do decide to take part in the re-test you will be contacted again a few weeks later by the lead researcher (Sophie).

What if I want to take part in the re-test?

If you want to take part in the re-test aspect of this research, (where you complete the same questionnaires again but a later date) you will be asked to provide an email address when you give consent to take part in the study. The lead researcher (Sophie) will then use this to contact you to give you all the information you need to complete the questionnaires again 3 weeks later. Once you have completed the questionnaires for the second time you will be given another debrief (on the website) which again summarises the research you have just taken part in.

How long will it take?

Completing the questionnaires will take around 30 minutes, although it may be longer or shorter as filling in the questionnaires is very individual. If you wish to take time with it then by all means, take as much time as you want. There is no race to complete them.

What if I can't get online or the website doesn't work for me?

If for whatever reason you are unable to get online or you have any problems with the website just email the main researcher (Sophie) on s.williams3@derby.ac.uk and let her know the problem and a postal address. She will then post you a paper copy with return postage.

What are the possible disadvantages or side effects of taking part?

Currently, there are no known side effects of completing a quality of life scale. To take part you will need access to a computer and the internet however the activity should not take long to complete.

What are the possible benefits of taking part?

We are trying to develop a tool which may help health professionals understand the impact of PCOS on your quality of life. This scale may also help researchers to measure the impact of PCOS on quality of life. We cannot promise that this study will help you, but the information we get from this study could help to improve the care of PCOS patients.

What if there is a problem?

We do not believe that participation in this study will harm you in any way. In the unlikely event that you are harmed by taking part in this research project, there are no special compensation arrangements. If you are harmed due to someone's negligence, however, then you may have grounds for legal action which you may have to pay for.

If you have a concern or complaint about any aspect of this study, you should speak to the research team and we will do our best to address your concerns (tel: 01332 592898). If you have a concern which you would like to take up with someone other than the research team, you can contact James Elander (tel: 01332 593048) who is the Head of the Centre for Psychological Research at The University of Derby.

Who is organising and funding the research?

The research is funded by Sophie Williams and is part of her PhD thesis.

Who has reviewed the study?

This study has been reviewed and given favourable opinion by the University of Derby Ethics Committee. If you have any questions or concerns about this study, you should discuss them with the research team (contact details below).

What do I do if I am interested in taking part in the research?

If you would like to take part in the research all you need to do is click on the website link (or continue on this page) and fill out the information and answer the questions. Alternatively, you can contact one of the research team by telephone or email (you can find these at the bottom of this sheet). At this point we will be able to explain the study in more detail and answer any questions you might have.

What happens if you change your mind?

Although your input to this research will be extremely valuable, participation is entirely voluntary and should you decide you no longer want to take part you are free to withdraw from the study at any time, before, during or up to two weeks after you have participated. If you have taken part in the re-test aspect of this research, you are still able to withdraw from the study at any time, before, during or after for up to two weeks after completing the re-test questionnaires.

What happens if you decide not to take part?

It is your choice whether you take part in the research or not. Participation is entirely voluntary. If you decide that you do not want to take part and have already participated all you would need to do is email the main researcher (Sophie) and provide your unique participant code. She can then withdraw any data attached to this code.

Will I be anonymous?

If you want to take part in this research you will remain anonymous and all identifying details shall be anonymised. You will be asked to provide a unique participant code which will attach to your information, in that way if you wish to withdraw, we will use to withdraw your data.

If you choose to take part in the re-test the main researcher and the research team will have access to your name and details however these will not be shared with anyone outside of the research team. Your data (the answers to the questions and information about your age etc) shall remain anonymous and shall be recognised by the unique participant code.

What will happen to the information that you give?

The information will be stored securely at the University of Derby for 10 years and only the research team will have access to it. All of your data will be anonymised. A summary of the data and the overall findings will be used in research papers and be submitted to the University of Derby as part of a PhD thesis. Results from the study will also feed into the development of health care services if appropriate. You will not be identified in any report or publication.

Where can I get more information about this research?

If you would like more information about this research please contact one of the research team on the details below.

Main Researcher: Sophie Williams
s.williams3@derby.ac.uk
01332 592089

r.knibb@aston.ac.uk
0121 204 3402

Professor David Sheffield
d.sheffield@derby.ac.uk
01332 592038

Dr Heidi Sowter
h.sowter@derby.ac.uk
01332 591749

Dr Rebecca Knibb

Appendix P: Scale development – consent form

Quality of Life Scale

Statement of Informed Consent

I understand that I have agreed to participate in a research study to develop and test a quality of life scale for women Polycystic Ovary Syndrome.

I have seen and read a copy of the project information sheet and have been given an opportunity to ask any questions about the study.

I understand that my participation in the study is voluntary, and that if I wish to withdraw from the study at any time I may do so up to two weeks after completing the questionnaires and up to two weeks after the re-test. I understand that I do not have to give any reasons or explanations for doing so. I have been provided with details of who I should contact if I wish to withdraw.

I understand that if I wish to take part in the re-test aspect of this study the research team will have access to my name and email address however all questionnaire data shall be recognised by a unique identifying code.

I understand that my personal data will be kept confidential and that all information collected for the research will be stored securely at the University of Derby on a password protected database. Only the research team have access to this.

I understand that these results may be disseminated through conferences and/or published articles. I understand that my data will remain anonymous at all times. I understand that the results of this research study will be written up as part of a PhD thesis and submitted to the University of Derby.

I agree to and understand the above statements (*participants are only able to select one*)

Yes No

If you wish to take part in the re-test please provide your email address below (this will only be seen by the research team and kept separately to your data).

I consent to taking part in the re-test (*participants are only able to select one*)

Yes No

Appendix Q: Scale development – debrief

The impact of PCOS on Quality of Life Scale Development

Participant Debrief

Thank you very much for taking part in this research study.

Your decision to participate is completely voluntary. Should you wish to withdraw from the research you may do so at any point, up to two weeks after participation. You will not need to give any reason or explanation for doing so. To withdraw your data simply contact the researcher or research team on the details below with your unique participant code (the three item code made up of numbers or letters).

Should you have any questions about the research please feel free to contact myself or the research team on the provided details. If you have lost your participant information sheet and would like another one please let me know and I will send you one.

If you would like more information about PCOS or have any worries about PCOS please contact your GP or visit www.verity-pcos.org.uk.

Many thanks

Sophie Williams
s.williams3@derby.ac.uk
01332592898

Dr Rebecca Knibb
r.knibb@aston.ac.uk
0121 204 3402

Professor David Sheffield
d.sheffield@derby.ac.uk
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Appendix R: Scale development – The PCOS QOL

The PCOS QOL

This scale has been specifically designed to measure quality of life for women with Polycystic Ovary Syndrome (PCOS). The questions in this scale are concerned with your PCOS, your health and health related issues. Please read and respond to every statement by selecting the option that reflects how you feel the most. There are no right or wrong answers, just choose the answer that shows how you feel best. If you feel a question does not apply to you, please select 'Does not apply'.

During the last four weeks how often have you:

	Usually	Often	Sometimes	Occasionally	Rarely	Not At All	Does Not Apply
Felt under pressure to have a child	1	2	3	4	5	6	7
Felt guilty for being overly aggressive towards a friend or family member	1	2	3	4	5	6	7
Over reacted to a day to day occurrence because of PCOS	1	2	3	4	5	6	7
Felt like you weren't a real woman because of your PCOS	1	2	3	4	5	6	7
Felt overwhelmed by your PCOS and depression	1	2	3	4	5	6	7
Felt depressed about how PCOS has impacted your life	1	2	3	4	5	6	7
Been worried about other people seeing your facial hair	1	2	3	4	5	6	7
Felt anxious about conceiving a child	1	2	3	4	5	6	7

Felt depressed over difficulties conceiving a child	1	2	3	4	5	6	7
Felt like less of a woman because of having PCOS	1	2	3	4	5	6	7
Had a short temper with your close friends and/or family	1	2	3	4	5	6	7
Felt like crying for no reason	1	2	3	4	5	6	7
Wanted to do something but haven't because of your PCOS	1	2	3	4	5	6	7
Felt depressed	1	2	3	4	5	6	7
Felt abnormal because of your PCOS	1	2	3	4	5	6	7
Felt like you don't know what to do to help yourself	1	2	3	4	5	6	7
Felt like you don't know what to do to control your PCOS	1	2	3	4	5	6	7
Felt like you hated yourself	1	2	3	4	5	6	7
Felt like your PCOS is in control of your life	1	2	3	4	5	6	7
Felt embarrassed about the way you look	1	2	3	4	5	6	7
Felt moody because of your excess hair	1	2	3	4	5	6	7

Felt depressed because of your hirsutism	1	2	3	4	5	6	7
Felt depressed because of your infertility	1	2	3	4	5	6	7
Spent a lot of time and energy removing excess hair	1	2	3	4	5	6	7
Felt depressed over your struggle to have children	1	2	3	4	5	6	7
Felt depressed because of your facial hair	1	2	3	4	5	6	7
Felt angry that you have PCOS	1	2	3	4	5	6	7
Been envious of women without PCOS	1	2	3	4	5	6	7
Felt embarrassed about having PCOS	1	2	3	4	5	6	7
Felt embarrassed by your facial hair	1	2	3	4	5	6	7
Felt like a failure because of your trouble concieving	1	2	3	4	5	6	7
Felt that it is unfair that you have PCOS	1	2	3	4	5	6	7
Struggled to cope with your PCOS and your other condition(s)	1	2	3	4	5	6	7
Been scared that you may not have children	1	2	3	4	5	6	7
Wanted to take part in a social activity but	1	2	3	4	5	6	7

haven't because of
your PCOS

Appendix S: Scale development – Hospital Anxiety and Depression Scale

Presented are sample items from the depression and anxiety subscales of the HADS.

I feel tense or 'wound up':	A
Most of the time	3
A lot of the time	2
Time to time, occasionally	1
Not at all	0
I still enjoy the things I used to enjoy:	D
Definitely as much	0
Not quite so much	1
Only a little	2
Not at all	3
I get sudden feelings of panic:	A
Very often indeed	3
Quite often	2
Not very often	1
Not at all	0
I can enjoy a good book or radio or TV programme:	D
Often	0
Sometimes	1
Not often	2
Very seldom	3

Appendix T: Scale development – The WHOQOL-BREF UK

Presented are samples of items from The WHOQOL-BREF UK

	Very Poor	Poor	Neither poor Nor Good	Good	Very Good
How would you rate your quality of life?	1	2	3	4	5

	Very Dissatisfied	Dissatisfied	Neither Satisfied nor Dissatisfied	Satisfied	Very Satisfied
How satisfied are you with your health?	1	2	3	4	5

	Very Poor	Poor	Neither poor Nor Good	Good	Very Good
How well are you able to get around?	1	2	3	4	5

	Very Dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very Satisfied
How satisfied are you with your sleep?	1	2	3	4	5

Appendix U: Scale development – demographic questionnaire

In the box provided please provide a unique identifying code. This should be 4 units made up of numbers and/or letters that you will easily be able to remember. Please keep a record of this, should you want to withdraw your data, this is the code you will need.

Please write your answer here:

Age

Please write your answer here:

What is your marital status?

Please choose **all** that apply:

- Married
- Civil Partnership
- Divorced
- Single
- Living with Partner
- Long term relationship
- Other:

Do you have any children?

Please choose **only one** of the following:

- Yes
- No

If yes, how many children do you have?

Please write your answer here:

-

And if you answered Yes, how old are your children?

Please choose **all** that apply:

- 0-2 years
- 3-5 years
- 6-8 years
- 9-11 years
- 12-15 years
- 15-17 years
- 18-20 years

- 21 and above

Have you adopted any of your children?

Please choose **only one** of the following:

- Yes
- No

If yes, how many?

Please write your answer here:

Are you pregnant now?

Please choose **only one** of the following:

- Yes
- No

If you answered yes, how many weeks are left until your due date?

Please write your answer here:

-

If no, are you currently trying to conceive?

Please choose **only one** of the following:

- Yes
- No

Have you received a diagnosis of PCOS from a doctor, specialist or other relevant health care professional?

Please choose **only one** of the following:

- Yes
- No

If yes, what tests did you have to get a diagnosis?

Please choose **all** that apply:

- Vaginal Ultrasound
- Abdominal Ultrasound

- Blood Test (this may be checking your androgen hormone levels or your glucose levels)
- Physical Exam (this may be checking your BMI, your waist measurement or signs of excess hair)
- Other:

What are the main PCOS symptoms you experience?

Please choose **all** that apply:

- Infertility
- Irregular Periods
- Hirsutism (Excess hair on the body)
- Acne
- Excess Weight
- Male Patterned Baldness or Thinning Hair
- Patches of Skin Discolouration
- Skin Tags
- Mood Swings
- Other:

What treatments/medications, if any, are you currently taking?

Please write your answer here:

What treatments/medications, if any, have you had or taken in the past?

Please write your answer here:

Have you received a clinical diagnosis (from a doctor or health professional) of Depression?

Please choose **only one** of the following:

- Yes
- No

If Yes, When?

Please write your answer here:

If Yes, have you received any treatment or medications for your depression? Please detail any medications or treatments you may have taken or received.

Please write your answer here:

Have you ever self harmed?

Please choose **only one** of the following:

- Yes
- No

If yes, have you self harmed recently (in the last 3 months)?

Please choose **only one** of the following:

- Yes
- No

Have you received a clinical diagnosis (from a doctor or health professional) of Anxiety?

Please choose **only one** of the following:

- Yes
- No

If Yes, When?

Please write your answer here:

If yes, what type of anxiety disorder have you been diagnosed with?

Please choose **all** that apply:

- Generalised Anxiety Disorder
- Obsessive Compulsive Disorder
- Post Traumatic Stress Disorder
- Social Anxiety Disorder
- Panic Disorder
- Other:

If Yes, have you received any treatment or medications for your anxiety?

Please write your answer here:

Have you ever been diagnosed with an eating disorder?

Please choose **only one** of the following:

- Yes
- No

If yes, when were you diagnosed?

Please write your answer here:

Appendix V: Intervention study- Invite to participate

Would you like to participate in a clinical trial to see if completing a positive psychology activity has an impact on quality of life for women with Polycystic Ovary Syndrome (PCOS)?

Positive psychology is described as the science of well-being and optimal functioning and previous research has shown that positive psychology activities, such as writing down three good things that happen to you in a day, can have beneficial effects on quality of life.

So, this intervention will use the three good things activity, where you write down three good things that have happened to you each day, for four weeks. This is to see if doing a positive psychology activity can have an impact on your quality of life. It will be run completely online and so having access to the internet is important but it also means that you can take part in the comfort of your own home. The research team will also contact you via email but you are free to call/email/write to them at any time if you have any questions or queries. This study has received ethical approval from University of Derby Psychology Ethics Committee. The study also follows the British Psychological Society requirements regarding ethics and also conforms to the regulations outlined in The Data Protection Act (1998).

To find more information or to take part please click here [link to website with info sheet/consent/demographics]

If you have any questions then all you need to do is contact Sophie Williams at s.williams3@derby.ac.uk or 01332592898.

Appendix W: Intervention study – information sheet

This will be printed on headed paper and available online.

Positive Psychology and Quality of Life Study

Participant Information Sheet

Introduction

You are invited to take part in an online research study to explore the use of positive psychology activities as a complimentary therapy for patients with Polycystic Ovary Syndrome (PCOS) and the impact practicing positive psychology activities can have on quality of life.

Several studies have shown that positive psychology activities, such as writing down three good things that happen to you in a day, can have beneficial effects on quality of life. This research will try to find out if a positive psychology activity has positive effects on quality of life in women with PCOS. If this study shows any benefits for participants we can then recommend this type of intervention for future patients or individuals who could benefit from an improved care service.

Who is doing this research?

The research is being undertaken by a multi disciplinary team from the NHS and the University of Derby. The research team includes Sophie Williams, a PhD student at the University of Derby; Professor David Sheffield, Assistant Head of Psychology Research Centre, Dr Rebecca Knibb, Senior Lecturer in Psychology at Aston University and Dr Heidi Sowter, Reader in Oncology at the University of Derby. It also includes Mr. Saad Amer, a Consultant Gynaecologist who runs the weekly PCOS clinic at the Royal Derby Hospital.

Why have you been invited to participate?

You have been invited to participate as you experience PCOS symptoms, are over 18 and live in the UK.

What does taking part in this research involve?

The aim of the research is to compare a group of participants who are taking part in a four week online course of a positive psychology activity (intervention group) and a group who don't take part in the positive psychology activity (comparison group). Agreeing to take part in this research would mean that you are prepared to be in either group (but don't worry, the intervention will be offered to all comparison group participants at the end of this study but we can't guarantee there will be any benefit from taking part in this study to you).

You should have also seen a post which will have on it a website address, if you go to the website you will be able to consent to taking part by ticking a box saying that you either 'Agree' or 'Disagree' to taking part. This will act as an online signature. After consenting to take part in this research you will then be asked straight away to fill in some information about yourself. Once you've done that you will be randomly placed by the research team in either the intervention group or the comparison group. The whole study will take place using the internet.

Those in the intervention group will then be invited to take part in a four week course of a positive psychology activity, where you will first be asked to complete some questionnaires. You will then be asked to write down three good things which have happened to you each day for four weeks. If you can, complete the task towards the end of your day, but if you can't do

it then, any time will be fine. You will be able to complete this on a website which will be provided for you.

When the four weeks is up participants in the intervention group will be asked to complete another set of questionnaires. Participants in the comparison group will just be asked to fill in the questionnaires at the start of the study and again 4 weeks after they initially consent to take part. If you are in this group you will NOT be asked to write about three good things every day. All participants will be contacted 6 weeks after the start of the study to gather further follow up information. At this point you will be asked to complete the questionnaire pack for a final time.

What if I can't get online?

This is an online study and so you will need to be able to access the internet to take part. If you are in the intervention group and one day are unable to get online to fill in your three good things you can write it down (on paper, on your phone, in a notebook etc) and email it to the researcher as soon as you are able to, stating which day the entry is for.

What if I forgot to do my three good things activity?

If you forget to do your three good things activity that's fine, just continue to do the three good things activity everyday as normal for the remainder of the intervention.

What if I cannot think of three good things?

Don't worry if you can't think of three good things, just do what you can. There are no rules on what a 'good' thing is; this may be as simple and small as a nice meal or the sun is shining; or as big as a promotion at work. It's completely up to you but if you can't think of three try for two or just one. If you cannot think of any, just say so in the area where you would normally write a good thing.

What is the procedure that is being tested?

We are trying to find out if practicing positive psychology activities can improve the quality of life women with PCOS. We are not anticipating any other therapeutic benefits such as an improved diagnosis.

What are the possible disadvantages or side effects of taking part?

Currently, there are no known side effects of taking part in a positive psychology activity. The positive psychology activity you will be asked to complete has been used previously in other psychology research. To take part you will need access to a computer and the internet however the activity should not take long to complete.

What are the possible benefits of taking part?

We are trying to find out if a positive psychology activity can benefit women with PCOS by helping them to manage symptoms of the condition, such as depression or anxiety symptoms and in turn to see if there is an impact on quality of life. We cannot promise that this study will help you, but the information we get from this study could help to improve the care of PCOS patients.

What if there is a problem?

We do not believe that participation in this study will harm you in any way. In the unlikely event that you are harmed by taking part in this research project, there are no special

compensation arrangements. If you are harmed due to someone's negligence, however, then you may have grounds for legal action which you may have to pay for.

If you have a concern or complaint about any aspect of this study, you should speak to the research team and we will do our best to address your concerns (tel: 01332 592898). If you have a concern which you would like to take up with someone other than the research team, you can contact the Head of Psychological Research, Professor James Elander (email: j.elanders@derby.ac.uk, tel: 01332593048)

Who is organising and funding the research?

The research is funded by the University of Derby and Sophie Williams. This research is part of Sophie William's PhD thesis.

Who has reviewed the study?

This study has been reviewed and given favourable opinion by the University of Derby Psychology Research Ethics Committee, and has undergone external peer review. If you have any questions or concerns about this study, you should discuss them with the hospital doctor involved with the study.

What happens if you change your mind?

Although your input to this research will be extremely valuable, participation is entirely voluntary and should you decide you no longer want to take part you are free to withdraw from the study at any time, before, during or up to two weeks after you have finished your positive psychology activity. You just need to email one of the research team to let them know and all your details will be removed from the study.

What happens if you decide not to take part?

It is your choice whether you take part in the research or not. Participation is entirely voluntary.

What will happen to the information that you give?

The information will be stored securely at the University of Derby for 10 years and only the researchers will have access to it. Although the research team will have access to your email address (only the research team will have access to this) all of your data will be stored under a participant identification code that you create. A summary of the data, the overall findings and any entries you make during the study may be used in research papers and be submitted to the University of Derby as part of a PhD thesis. Results from the study will also feed into the development of health care services if appropriate. You will not be identified, nor will any identifying details be used, in any report or publication. Information entered online whilst participating in the study will be stored online within the computer software and shall be accessible only by the research team and will be password protected.

Where can I get more information about this research?

If you would like more information about this research please contact one of the research team on the following details.

Sophie Williams
s.williams3@derby.ac.uk
01332 592089

Professor David Sheffield
d.sheffield@derby.ac.uk
01332 592038

Dr Rebecca Knibb
r.knibb@aston.ac.uk
0121 204 3402

Dr Heidi Sowter
h.sowter@derby.ac.uk
01332 591749

What do I do if I want to take part?

If you want to take part all you need to do is contact Sophie Williams on the details above. Or, alternatively you can go directly to the study website here (enter website address), read more information and begin to take part.

Will I get a summary of the results?

Yes when the study is completed the research team will email you a summary of the results.

Can I get advice from the research team about my PCOS?

Unfortunately the research team is unable to offer you any advice on PCOS. If you do need any advice or help we would recommend you contact your doctor or relevant health professional.

What if I become distressed during the study?

It is not anticipated that there will be any reason for you to become distressed during this study but if you do please contact your GP or relevant health professional. Alternatively, you can get support from the UK PCOS charity, Verity.

Appendix X: Intervention study – consent form

Positive Psychology and Quality of Life in PCOS

Statement of Informed Consent

I understand that I have agreed to participate in a research study exploring the impact of positive psychology on the quality of life of women with Polycystic Ovary Syndrome.

I have received a copy of the project information sheet (dated x) and have been given an opportunity to ask any questions about the study.

I understand that my participation in the study is voluntary, and that if I wish to withdraw from the study at any time I may do so up to two weeks after participation, and that I do not have to give any reasons or explanations for doing so. I have been provided with details of who I should contact if I wish to withdraw.

I understand that my personal data will be kept confidential and that all information collected for the research will be stored securely at the University of Derby on a password protected database or a locked filing cabinet. Only the research team have access to this.

I understand that the research team will have access to my email address however all my details will remain anonymous and no identifying information shall be published.

I understand that verbatim quotes from my entries into the three good things activity may be published. However these will remain anonymous and all identifying details will be removed.

I understand that these results may be disseminated through conferences and/or published articles. I understand that my data will remain anonymous at all times. I understand that the results of this research study will be written up as part of a PhD thesis and submitted to the University of Derby.

I am happy to take part in the study and acknowledge that I may be randomly allocated to either the positive psychology intervention condition or the control condition (no positive psychology intervention).

I have read and understood all the information above and agree to take part in this study.

Participants were asked to select one

Yes/No

Appendix Y: Intervention study – debrief

Positive Psychology and Quality of Life Study

Participant Debrief

Thank you very much for taking part in this research study.

Your decision to participate is completely voluntary. Should you wish to withdraw from the research you may do so at any point, up to two weeks after participation. You will not need to give any reason or explanation for doing so. To withdraw your data simply contact the researcher or research team on the details below with your unique participant code (the four item code made up of numbers and/or letters).

Should you have any questions about the research please feel free to contact myself or the research team on the provided details. If you have lost your participant information sheet and would like another one please let me know and I will send you one.

If you were a member of the control group and would like to access the intervention please contact Sophie Williams on the details below who will give you all the information you need.

If you would like more information about PCOS or have any worries about PCOS please contact your GP or visit www.verity-pcos.org.uk.

Many thanks

Sophie Williams
s.williams3@derby.ac.uk
01332592898

Dr Heidi Sowter
h.sowter@derby.ac.uk
01332591749

Professor David Sheffield
d.sheffield@derby.ac.uk
01332592038

Dr Rebecca Knibb
r.knibb@aston.ac.uk
0121 204 3402

Appendix Z: Intervention study – evaluation questions

Evaluation

The following questions aim to provide the research team with more information about the positive psychology study so they can understand how it may be improved. Please answer the questions considering your experiences with the positive psychology intervention.

Were you in the intervention or control group? Please select one.

Intervention

Control

Don't remember

Did you find the positive psychology intervention study enjoyable?

Likert scale 1 – 7

1 = no I didn't enjoy it

7 – I enjoyed it very much

How easy did you find it to complete the intervention (including the positive psychology activity and/or any questionnaires you completed)?

Liker scale 1 – 7

1 = very difficult

7 = very easy

Please tell us about your experience on the positive psychology intervention. Please consider what was good and what was bad? [open text]

Are there any other comments you would like to make: [open text]

Appendix AA: Intervention study – PREC approval letter (87-13-SW)

Approval Letter: Psychology Research Ethics Committee

University of Derby

Date: 21st August 2013

Dr Frances A. Maratos
Chair, Psychology Research Ethics Committee, University of Derby

Dear Miles,

Ethics Ref No: 087-13-SW

Thank you for submitting this revised application to the Psychology Research Ethics Committee.

I have now reviewed the revised documents you sent following the feedback you received on your initial application, and I am satisfied that all of the issues raised have been dealt with. The application can now therefore be approved.

If any changes to the study described in the application or supporting documentation is necessary, you must notify the committee and may be required to make a resubmission of the application.

Good luck with the study.

Yours sincerely

F. A. Maratos

Frances A. Maratos