Managing Health, Femininity &Fertility

Self-care Practices among Women with Polycystic Ovary Syndrome

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Summary

In this research project, I studied the self-care practices women with polycystic ovary syndrome (PCOS) engage in to cure, manage and prevent symptoms. From earlier studies, it is known that PCOS can affect women in their self-esteem and sense of femininity. However, much less is known about how women with PCOS deal with the consequences of the condition in daily life, and the forms of self-care they engage in. My aim in this research is twofold. First of all, I aim to provide insight into the lived experiences of women with PCOS and the ways in which the condition affects them on a daily basis, directly and indirectly. Following from this, I explore how women with PCOS perceive and perform their own (in)ability to manage it and the forms of 'self-care' they use to do this. Through interviewing women and asking about self-care regimens, I found that self-care is practiced in many different ways and for different purposes, such as maintaining femininity and beauty, striving for fertility, managing weight, dealing with physical discomfort and preventing future health risks. These different purposes of self-care are strongly interrelated, and femininity in appearance is viewed as part of female health. Self-care practices take place both on the prescription of health care professionals (e.g. doctors, nutritionists or dermatologists) as well as on participants' own initiative. As existing medical treatment does not always address the specific concerns and needs of a woman with PCOS, women search for information themselves on the internet. This information provides them with tools for the management of symptoms, but can also be experienced as confusing or frightening. Whereas some women are unsatisfied with the dominant medical perspective that there is little they can do to manage symptoms, the notion that PCOS is completely manageable through lifestyle, as communicated on some web pages, does not fit their experiences either. In a context of 'healthism', the individual is rendered both responsible for as well as capable of managing health, and is expected to make informed health choices in a context of contrasting health information. However, in this study I found that this not have to imply that individuals also view themselves as fully capable of managing their own health. As a result, although many forms of self-care are practiced by women with PCOS, these practices are surrounded by a large uncertainty about its effects at the same time.

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Chapter 1: Introduction

In the autumn of 2013, at age 22, I was diagnosed with polycystic ovary syndrome. The diagnosis followed upon a couple of months in which I experienced changes in my body that I was not happy with: My skin started to rash while it had never done before, my hair thinned out and my arms were getting darker. An ultrasound scan in the hospital confirmed what I had already suspected after googling my symptoms: I had cysts in my ovaries, and was diagnosed with polycystic ovary syndrome (PCOS). As I was told by the gynecologist that there is no definite cure for PCOS, I spent many hours searching on the internet, trying to find out what I could do myself to stop these changes on my body from happening, and tried out many different remedies in the hope they would work. I tried out different diets and supplements, however often unsuccessfully. Eventually I found a herbal supplement that worked, and still benefits me. Looking back in time, I realize that the experience of developing PCOS has made me much more conscious about my body, my health, my appearance and whether I could influence these things through my own behavior.

Following from my own experience of dealing with a chronic health problem and navigating through all sorts of do-it-yourself remedies, I decided to conduct my research on the experiences and self-care practices of women suffering from PCOS. My aim in this research is twofold. First of all, I aim to provide insight into the lived experiences of women with PCOS and the ways in which the condition affects them on a daily basis, directly and indirectly. Following from this, I explore how PCOS women perceive and perform their own (in)ability to manage it and the forms of 'self-care' they use to do this.

Polycystic ovary syndrome (PCOS) is an endocrine disorder characterized by the presence of cysts in the ovaries. In addition to the presence of cysts, it may include symptoms such as 'infertility or higher risk of miscarriage, hirsutism ('excess' hair growth), amenorrhea or oligo-menorrhea (irregular or no menstrual cycle), menorrhagia (excessive menstrual bleeding), anovulation, weight gain or obesity, acne vulgaris, androgenic alopecia (male pattern hair loss), insulin resistance and excess androgen production' (Kitzinger & Willmott 2002: 349). The condition was first described by the American gynecologists Stein and Leventhal (1935). The exact diagnostic criteria of the disease changed over time, and right now the 2003 Rotterdam criteria are guiding the diagnosis of PCOS, which state that at least two of the following symptoms should be present: 'polycystic ovaries on ultrasound, high androgen levels/clinical hyperandrogenism and menstrual irregularity'[1].

[1] Revised 2003 consensus on diagnostic criteria and
long-term health risks related to polycystic ovary syndrome. *Fertil Steril* 2004; 81: 19–25.

PCOS is estimated to affect '9–18% of reproductive aged women in Australia and internationally' (Gibson-Helm et al 2014: 545). As diagnosis with PCOS is based on the presence of a combination of symptoms, PCOS sufferers cannot be seen as a clearly demarcated group. As a result, PCOS is a 'heterogeneous condition' (Kitzinger & Willmott 2002: 349) that affects women in diverse ways.

In addition to biomedical research, some social scientific studies have focused on this condition, although it has not received much attention within the field of social science yet. The social scientific work on this condition is mostly concerned with the self-image of women with PCOS in relation to dominant ideas around womanhood and beauty (see for example Kitzinger & Willmott 2002, Amiri et al. 2014, Sanchez & Jones 2016 and Weiss & Bulmer 2011).Amiri et al. (2014),for example, found that Iranian women with PCOS were challenged in their perception of themselves as 'feminine' due to their excess body hair. Similarly, as Kitzinger & Willmott (2002: 349) describe based on their study with 30 women with PCOS, the three main symptoms commonly experienced in PCOS (excessive hair growth, infertility and irregular periods) often result in feelings of 'abnormality' in these women and the sense of not being a 'proper' woman. Kitzinger & Willmott relate these sentiments to dominant ideas around gender, in which 'smooth hairless bodies and faces' are seen as an integral part of femininity, as well as the ability to bear children. Being unable or less able to conform to these standards results in feelings of shame in women with PCOS. Kitzinger & Willmott (ibid: 359) also stress that the dominant images of femininity do not affect PCOS women only, but exert power over all women. However, for women with PCOS, normative femininity is harder to attain, and sometimes unachievable. Due to this inability to fully attain what is considered normal, PCOS radically challenges dominant understandings around what constitutes 'womanhood' (e.g. in relation to smooth skin), which appears as 'natural' in daily life. Based on these findings, I describe how women with PCOS relate to this notion of 'womanhood'. As PCOS has 'masculinizing' effects on the body and reduced fertility can affect one's sense of femininity, I assessed if and how the strive to attain normative femininity influences the behavior of women with PCOS to engage in certain self-care practices.

As Gibson-Helm et al. (2014) point out, little research has been conducted into the diagnosis experience of women with polycystic ovary syndrome and their encounters with medical treatment. In their own study into the experiences of women with PCOS, based on a sample of 210 Australian women, they speak of an 'often prolonged and frustrating diagnostic experience' (ibid: 547) as '24% of women, PCOS diagnosis took >2 years and 39% saw three or more health professionals before diagnosis was made' (ibid: 545). Moreover, they point out that 62% of women are dissatisfied with the information provided to them after diagnosis, especially the lack of information on the role of lifestyle (ibid: 547).Given the fact that lifestyle is mentioned in their study as a topic that women would like to receive more information about after diagnosis, studying the self-care practices of PCOS

women – including lifestyle adjustments – can help to give insights into their specific needs and concerns and how they can be addressed during medical consults more sufficiently.
Therefore, the following research question guided my study:

Which forms of self-care do women with polycystic ovary syndrome use to cure, manage and prevent the symptoms of PCOS?

This research is relevant in two more ways. In a broader sense, this study can shine light on the way patients deal with a chronic condition for which there is no definite cure and the uncertainties that come along with it. In an age of a growing emphasis on health as an individual responsibility (Mitchell 2010) and many, contradictory discourses on health and risks exist simultaneously, it can show how patients navigate through the information around make their choices for care. Care is not something people undergo passively, but the responsibility for one's health turns the patient into an 'active, choosing, empowered agent' (ibid: 112). How do people deal with this responsibility? How is information on health being selected and evaluated, and what role do media such as the internet play in providing information?

Finally, studying the motivations of women with PCOS to engage in certain forms of (self)-care can give insight into understandings around 'health', 'beauty', 'femininity' and 'well-being' and, especially, how they relate to each other. How does a medical condition like PCOS affect the way sufferers perceive themselves, their identities and their well-being? How do dominant societal understandings around these matters shape their experiences? These and other questions will be addressed in this thesis.

Chapter 2: Theoretical framework

In this theoretical framework, I will first give insight into the understanding of polycystic ovary syndrome in biomedical research and the treatments that are offered to PCOS sufferers. This background is relevant for understanding the self-care practices women with PCOS engage in and how they relate to biomedical practice. After this I will discuss several concepts that I believe are important in this study: Gender performativity, healthism, self-care, risk society and de-professionalization of medicine.

PCOS, etiology and treatment

As Setji & Brown (2014: 912) point out, during the last three decades, research on PCOS 'has launched it from relative medical obscurity to a condition increasingly recognized as common in internal medicine practices'. Far from being a condition of the ovaries solely, PCOS is described as affecting multiple bodily systems, and as associated with complications including 'insulin resistance and diabetes, hyperlipidemia, hypertension, fatty liver, metabolic syndrome, and sleep apnea' (ibid). Little is known about the etiology of PCOS, but a few possible causes are mentioned in the literature (Goodarzi et al 2011).

'Insulin resistance' is mentioned as a potential factor leading to PCOS (Goodarzi et al 2011). Insulin resistance refers to a condition in which body cells are resistant to insulin action, resulting in an overproduction of insulin to lower blood sugar levels. This overproduction of insulin can induce excess testosterone production (Marshall & Dunaif 2012), leading to the manifestation of internal and external PCOS symptoms (e.g. excess body and facial hair, acne). Therefore, improving insulin sensitivity can be part of the treatment of PCOS symptoms. However, more research should be conducted into the clinical relevance of insulin resistance in non-obese women, and the use of insulin sensitizing drugsfor women with PCOS is contested (ibid).

For women who are not trying to conceive, the most important treatment option is the use of the birth control pill, 'as the first-line therapy for menstrual abnormalities, hirsutism and acne in PCOS'(Oria & Palomba 2014: 131). In addition, weight loss in overweight and obese women is mentioned as an important part of the treatment (Oria & Palomba 2014, Setji & Brown 2014, Moran et al. 2017, Marshall& Dunaif 2012, Van Hooff et al. 2005). Weight gain is mentioned as a cause as well as an effect of PCOS (Moran et al. 2017). On the one hand, overweight worsens insulin resistance, resulting in the production of excess testosterone and increasing PCOS symptoms. On the other hand, the hormonal imbalances resulting from PCOS may cause weight gain (ibid).

Because of the effect of overweight on hormonal balance and insulin resistance, lifestyle modifications in terms of diet and exercise for the purpose of weight loss are seen as 'crucial' in

overweight and obese women, and can result in a spontaneous restoration of the menstrual cycle (Oria & Palomba 2014: 131). However, lifestyle adjustments are usually not being recommended to non-overweight women, as very little data exists on different types of diets and its effects (ibid).

In terms of fertility treatment, The Dutch Society for Obstetrics and Gynecology (2005) mentions the following treatment options: clomiphene citrate tablets (Clomid), gonadotrofin injections, electrocoagulation of the ovaries and the use of metformin, an insulin sensitizing drug that can help promote ovulation in PCOS. As becomes clear from the literature, there is no single cure for PCOS, and treatment 'should be tailored to the patients' and the physicians' therapeutic goals' (Orio & Palomba 2014: 131).

Gender performativity and beauty practices

An important concept for understanding gender in this study, is 'gender performativity' as described by Judith Butler (1990). The core argument that Butler makes with the use of this concept, is that gender identities should not be viewed as 'essential' or natural, but rather are constituted by repetitive acts that makes them appear natural. In this way, the illusion of a true gender identity is created through 'a narrative sustained by the collective commitment to perform, sustain, and produce polar and discrete genders as a cultural fiction and punishments resulted from not 'playing your part' and agreeing with these fictions' (White 2015: 318). The way people perform gender is informed by social norms, and there is only limited space to manoeuver within them, according to Butler.

Gender is performed, amongst other things, through appearance (for example in terms of clothing, hairstyles, make-up, beard and mustache growth et cetera) in which certain features are identified as 'feminine' or 'masculine'. Notions around femininity and masculinity go hand in hand with ideal types around these two concepts, which are different per context. Although the acquiring of a culturally acceptable body out of a natural body always requires work to be done (Sharma & Black 2001: 100), there is a large imbalance between men and women in this respect. As Black & Sharma (2001) point out, 'on a day to day routine level men are not required to paint, moisturize, deodorize and de-hair their bodies in order to appear masculine' (ibid: 100), leading them to argue that while 'men are real', 'femininity is a state to be constantly sought' (ibid). This necessity to 'seek femininity' is related to a discrepancy between the natural body of a woman and what Toerien et al. (2005) call 'normative femininity'. One aspect of normative femininity, for example, is the idea that the woman's body should be hairless, which is not the 'natural' state of being for many women, even though it should appear as something natural. Toerien et al. (2005) point out that the removal of hair, as many other things, is 'part of the taken-for-granted work of producing an 'acceptable' femininity' (ibid: 399). Therefore, not only the outcome of a certain bodily ideal can be seen as part

of ‘normative femininity’, but also certain practices that are ‘needed’ to achieve that, as they are seen as normal practices to engage in for women (e.g. brushing the hair, shaving the legs). Therefore, I feel that the practices to achieve an acceptable femininity can be seen as a way of performing gender in itself. I believe that the perception of gender as actively performed rather than essential is relevant in the study of polycystic ovary syndrome as PCOS disrupts the idea of a ‘natural’ femininity. Just like other women, women with polycystic ovary syndrome engage in beauty practices in order to attain to normative femininity. But unlike many other women, women with polycystic ovary syndrome often do not completely succeed in this. In addition to that, women with polycystic ovary syndrome sometimes have to engage in practices which are not seen as regular female beauty practices, such as shaving one’s face. As a result, polycystic ovary syndrome challenges the illusion of a normative femininity that can be easily produced with a set of bodily practices, and therefore challenges dominant understandings of ‘womanhood’.

Health as an individual responsibility: On ‘healthism’ and self-care

‘Healthism’ is a term that has been used to refer to a societal shift in thinking about the responsibility for health, in which this responsibility shifts from the level of the state to the individual (Crawford 1980). In this perspective, ‘health’ is both an active process which the individual needs to engage in, as well as a commodity that people have to purchase by buying the means to stay healthy (Hurd Clarke & Bennett 2012: 213). On the one hand, this provides the individual with agency and renders the individual capable of making decisions about personal health management. One the other hand, it also blames the individual when good health cannot be achieved (Crawford 1980). This shift in thinking about health and responsibility has an impact on health care on many levels.

Part of the shift in the responsibility for health, is a growing emphasis on self-care when dealing with chronic illness. In a society in which health is seen as an individual responsibility, dealing with a chronic condition requires ‘individuals to monitor their symptoms, adhere to prescribed treatments and medication regimens, cope with physical limitations and emotional consequences of disease, discipline their bodies through diet, exercise, and other lifestyle modifications, and seek expert advice and intervention only where appropriate.’ (Hurd Clarke & Bennett 2012: 212). In their study into self-care practices of elderly people living with chronic conditions, Hurd Clarke & Bennett (2012) describe several motivations for the elderly people to engage in forms of self-care, including alterations to diet or daily exercise. According to their study, self-care takes place when the limits of the existing medical care have been reached, but the participants also saw it as a moral responsibility to take care of themselves. Engaging in self-care practices provides the patients with a sense of agency as well as independence.

Self-care is a rather broad concept that has been defined and operationalized in different ways by different authors. A common definition of self-care is the one introduced by the World Health Organization, in which self-care is defined as: 'the activities individuals, families and communities undertake with the intention of enhancing health, preventing disease, limiting illness, and restoring health' (World Health Organization 1983: 2, quoted in Hurd Clarke & Bennett 2012: 212).

Although I believe the above definition is useful as it incorporates a broad range of self-care practices that I encountered, I would like to conceptualize 'self-care' even broader in this study to also include practices that are aimed at 'coping with' or 'managing' illness, rather than curing or limiting it. As many symptoms of PCOS are not directly curable or preventable, the women in this study regularly engage in practices that are rather aimed at dealing with the symptoms. Examples include practices for pain management or use of make-up to increase self-esteem in the context of facial hair. Describing such practices as self-care practices, I base myself on the approach taken by Roberto et al. (2005) in their study on the 'coping strategies' of elderly women in dealing with multiple health conditions. Roberto et al. (2005) describe 'external strategies' of coping such as herbal medicine use, dietary adjustments and attending support groups, but also 'internal strategies', such as adherence to spirituality, adjusting expectations in relation to their abilities, and positive thinking. All of these strategies, both internally and externally, are ways of 'coping' with a chronic illness that cannot be fully cured.

In this study, I assess what types of self-care practices women with PCOS engage in, how self-care stands in relation to biomedical care, and how participants view their own agency in relation to managing their PCOS symptoms.

Risk society, de-professionalization and health

The German sociologist Ulrich Beck is one of the leading theorists in the sociology of risk. Beck (1992) describes how the nature of risk has changed over time. He uses the word 'risk' to refer to hazards or danger. Whereas hazards and danger were perceived as inevitable and uncontrollable in pre-modern times, in early modernity, they became more and more calculable with the development of science (Beck 1995 in Lupton 2013). In late modernity, however, risks become more and more elusive and incalculable due to their globalized nature, a situation Beck (1992) refers to as 'risk society'. In contrast to risks in early modernity, contemporary threats 'are often open-ended events, rather than events that have a foreseeable end' (Lupton 2013: 81). At the same time, there is a recognition that contemporary risks are the outcome of human action and modernity itself, through processes such as industrialization, globalization and over-accumulation. Therefore, risks are 'politically reflexive' (Beck 1992: 21); they inspire self-critique and attempts to transform society.

Examples of contemporary, globalized risks include climate change, epidemics or financial crises. Such risks are characterized by uncertainty about their cause, development and the role of institutions in preventing or managing them (ibid: 82). Scientist fail to provide satisfying answers to risks, which results in the loss of authority in risk assessment of science as an institution (Beck 1995: 125-126 in Lupton 2013: 83).

The uncertainty surrounding contemporary hazards results in contradictory expert knowledges, in which the explanations, solutions and severity of certain risks are a site of contestation (ibid). In relation to health risks, this means that a lot of contrasting information is provided about how to live healthy and prevent illness. This goes hand in hand with processes of 'proletarianization' and 'de-professionalization' of medicine, characterized by 'a demystification of medical expertise and increasing lay skepticism about the health professionals' (Hardey 1999: 821). Several scholars (see for example Hardey 1999 and Kivits 2009) have studied the role of health information on the internet in these processes. In his case study on internet use as a source of health information, Michael Hardey (1999) found that the internet is both a site for the exercise of medical authority, as well as for challenging existing medical knowledge and spreading new knowledge (ibid: 823). Therefore, according to Hardey, 'internet forms the site of a new struggle over expertise in health that will transform the relationship between the health professions and their clients' (ibid: 820). As 'the equity of presentation offered by the Internet dissolves the boundaries around areas of expertise upon which the professions derived much of their power' (ibid: 827), concerns are raised about the quality of the information provided. On the internet, individuals are tasked with evaluating the usefulness and quality of the information themselves. Selecting relevant information and ignoring other sources, readers are actively involved in constructing a 'narrative' around their health. Similarly, in her study on the relationship between internet use and health experience, Joëlle Kivits (2009: 673) found that 'agency is manifest in study participants' choice of both becoming more informed as well as having the possibility of ignoring information'. This agency in selecting and spreading health information goes hand in hand with an individual responsibility for health, as mentioned in the previous section. The concepts of 'risk society' and 'de-professionalization' as described above are relevant for studying self-care practices in women with PCOS, because the choices in relation to self-care are made in a context in which there is contrasting information on risk and health matters, and the individual patient is tasked with evaluating the existing health discourses in order to find a cure.

Chapter 3: Methodology

Operationalization

There are a few commonly used terms and phrases in this study that require clarification: self-care, 'cure, manage and prevent symptoms', agency, risk and 'sense of femininity'.

I interpret the concept of 'self-care' broadly by focusing on all practices that relate to preventing, curing, and managing the symptoms of PCOS, whether this concerns external forms of care (e.g. skin therapy, hair laser removal), the use of complementary and alternative medicine (e.g. herbal supplement), adjustments in lifestyle or otherwise remedies to relieve physical and emotional discomfort or to improve fertility. In part, practices of self-care were assessed with the use of a questionnaire (see appendix 2), in which participants were asked to fill in what they consumed during two days in terms of food, supplements and body products. However, during the interviews I found out that self-care can also take forms that were not included on the questionnaire (e.g. using a heat compress to relieve pain), and therefore the questionnaire covers only part of the self-care practices, albeit an important part. I use the phrase 'cure, manage and prevent' in my research question to refer to both 'reactive' and 'pro-active' forms of self-care (Ziguras 2009). Whereas reactive self-care serves to manage or relief existing symptoms, pro-active self-care is aimed at preventing symptoms that might occur in the future. As PCOS has been linked to different kinds of long-time health issues, it is important to assess how this influences the perception and self-care practices of PCOS women as well. The concept of 'agency' has been defined in many different ways by different authors. Here, I would say it relates to the capability of participants (or sense thereof) to exert influence over their own situation in terms of health, well-being, behavior or life in general, and the extent to which participants feel that they can make choices about doing so. For example, parts of the interviews in which participants spoke about the amount of 'control' they had, the extent to which they believed they had a 'choice' to engage in certain behaviors and whether they ascribed their physical or emotional state to their own actions, were analyzed in terms of agency. However, although I believe these factors are relevant for analyzing the concept of agency, I am aware that this is only one way to perceive agency, and might have its limitations. Talking about 'risk', I am referring to perceptions of participants on possible future health hazards, or other phenomena that are experienced negatively (e.g. infertility). In relation to risk, I studied how participants estimate the chances that they will be affected by these factors, and how this informs their behavior. Finally, 'sense of femininity' relates to the extent to which women in the study feel feminine, mostly in relation to visible PCOS symptoms. Whenever a woman mentioned that she felt 'less feminine' or

‘unfeminine’, I asked her what she meant by this and why she felt that way, to get insight into how she perceives femininity and how this stands in relation to her PCOS symptoms.

Sampling

Participants were sampled using different sources, including a post in a facebook group related to PCOS (‘PCOS Nederland – België’), an announcement on a Dutch website about fertility issues (www.freya.nl), an advertisement I spread around the university campus and through contacting a high number of owners of self-care blogs on PCOS. Moreover, I used my own facebook timeline to find participants and asked others to spread my message as well. I did not use any specific inclusion criteria except for having the diagnosis PCOS. Initially, I guided my search for participants mostly towards women living in The Netherlands, because I prefer live interviews over Skype interviews. However, as I noticed that it was not easy to find enough participants that way, I decided to plan Skype interviews as well, which enabled me to include women living abroad. Because many of the self-care blogs I contacted are owned by American women, there are relatively many American women in my sample (n=7). It is hard to say to what extent my sample is representative of women with PCOS, because the manifestation of PCOS is very diverse. Based on what is known on PCOS, though, I believe that ‘thin’ women are overrepresented in my sample, as about 50% of PCOS women are overweight or obese (Gambineri et al. 2002). In my sample, only four women were currently overweight or obese, although more of them had struggled with overweight in the past. I have no clear explanation for this difference in numbers, but it is important to bear this in mind as body size can certainly have an impact on the experiences of health and (self)care.

Research methods

My main research method in this project was in-depth interviewing. I interviewed 17 women. Because many participants lived far away or even abroad, 10 of the 17 interviews were conducted through Skype, whereas the remaining 7 interviews were held face to face. Concerning the nationalities of participants, 9 women were Dutch, 7 American and 1 woman was Chilean, but lived in The Netherlands. Interviews lasted between half an hour and one and a half hour and were fully recorded and transcribed with the permission of the participants. All participants have been assigned a pseudonym to ensure confidentiality. Two participants chose their own pseudonym after I asked them if they had a preference, for the other participants I picked a name. I used an interview guide (see appendix 1) consisting of 17 questions which were elaborated on during the interview. The

interview started with questions about the diagnosis of PCOS and what preceded this diagnosis. After that, we discussed the symptoms she experienced and how these had an impact in daily life. Questions included 'How do you deal with the symptoms you experience?' and 'At which moments do you feel most affected by PCOS?'. In the next part of the interview, we would discuss experiences with medical treatments and self-care practices, which I split up into a couple of separate questions (Do you receive any form of regular medical treatment, or have you done so in the past? Do you receive any form of alternative treatment, or have you done so in the past? Are you making any adjustments in terms of lifestyle (e.g. diet) which are related to PCOS? Have there been any changes in your daily care routine since you struggle with these symptoms?). The final part of the interview was usually about how she talked about her experiences with people in her environment, and her use of internet as a source of information or for contact with fellow sufferers.

I asked women to show me through their daily routines, by writing down what they do and consume in terms of diet, body products and medicine/supplement use and discussed that during the interview. To this end I used a questionnaire (see appendix 2) which asked participants to keep track of all practices related to external body care, (regular and alternative) medicine use and lifestyle during two days, from which one working day and one day in the weekend. During the interview, I asked them to explain more about their daily routines and whether and how a certain practice related to PCOS symptoms. However, as many of the Skype interviews were planned on a short term (one day in advance or even on the same day), in the end I asked to fill in the questionnaire only in interviews that were planned longer in advance (n=10), as filling in this questionnaire takes two days. Of the participants I asked to use this method, 8 managed to do so. In the remaining interviews, I walked through the questionnaire with the participant and gained insight into their self-care practices by asking about her diet, supplement use and body care products during the previous days. I am aware of the fact that this difference in method to assess self-care practices (filling out a questionnaire versus asking about this during the interview) influences participants' report, and that is a limitation for making comparisons between different participants. However, it is important to stress here that the use of the questionnaire was not intended to gather quantifying and comparable information about practices, but rather served as a practical tool to discuss these practices during the interview.

A final research method was the analysis the self-care blogs on PCOS, to assess how PCOS was explained on these pages, as well as the advices (e.g. in terms of lifestyle) that were provided to manage it. I included this method as online blogs are a commonly used source of information for PCOS sufferers, and providing some insight into their content is useful for understanding the influence of these blogs on the women in the study. I analyzed 25 of these pages

(see appendix 3 for the list of blogs) and searched for patterns in the understandings around causes of PCOS, symptoms and the possibilities for self-management on these pages. Based on this analysis, I provide an insight in the discourses of self-care blogs in chapter 6 and highlight the content of two popular pages. In addition, I analyzed the content of a facebook group for women with PCOS living in The Netherlands and Belgium, 'PCOS Nederland-België'. I asked the moderator of this page for permission to do so. However, for reasons of informed content and privacy I will not share any concrete posts on the page, but rather describe some general tendencies.

Data analysis

I analyzed the interviews and web pages using discourse analysis. As Sanna Talja (1999: 459) describes in relation to discourse analysis, it 'does not take the individual as the principal unit of analysis, but strives to recognize cultural regularities in participants' accounts to examine the phenomena studied at a macro-sociologic level'. I tried to do that as well, by viewing the statements of participants in the context of dominant discourses around health, agency, femininity, risk et cetera. At first I used 'open coding' in which labels derived from the data (O'Reilly 2012: 203) and were different for every interview. These initially open codes were descriptive rather than interpretative, and included labels such as 'wears hairpiece to cover up hair loss' or 'takes herbal medicine against pain'. After the process of open coding I switched to more 'focused coding' system, in which I used the general and analytic labels and I established (e.g. 'fear of future health risks', 'sense of femininity' or 'doubts own influence'). Based on the analyses of the interviews throughout the process, I slightly adjusted my research questions to exclude questions that did not work during the first interviews (mainly in relation to one's body image, see appendix 1) and paid more attention to topics that turned out to be relevant, such as the process of information seeking. Therefore, I worked in an inductive-iterative manner (ibid: 30), in which the analysis of data and gathering new data alternate each other.

Reflection on my own position

From an interpretivist epistemology, I believe that the outcome of this research should not be viewed as an objective reflection of reality, but rather as a product of the interaction between researcher and participants. Therefore, I believe it is important to provide some reflection on my own position and the methodological and ethical issues that my insider's status as PCOS sufferer brings about. Wherever possible, I tried to inform the participant about my own diagnosis prior to

the interview. If not, I told the participant about this during the interview. At the end of many interviews, participants asked about my experiences after which I told something about my situation. Sometimes my answers sparked new responses in the interlocutor, after which we continued the interview and discussed new topics based on the experiences that I shared.

Referring to his own insider status when conducting qualitative interviews with lesbians and gay men, Michael LaSala (2003) discusses the strength and limitations of this position as a researcher. An advantage of this position is the fact that an insider might be more open to *emic* understandings of participants. Whereas researchers from outside the research population sometimes take the ideas of the participants not so serious, researchers with an insiders' status are more likely to see the value of the participants' own conceptions (ibid: 17). Another advantage of having an insiders' perspective is the fact that participants trust you more, although this can also work the other way (ibid: 19). In my research, I felt that my own status as PCOS sufferer provided me trustworthiness, and some participants explicitly stated that the fact that I had PCOS influenced their choice to participate, as they assumed that I would understand the issues they dealt with, and it was less awkward to discuss personal and shameful matters (e.g. body hair) with me. At the same time, I felt that based on this, participants sometimes assumed that I understood how they felt in certain situations. Therefore, I had to make sure to ask about these feelings explicitly.

A related disadvantage of the insider status that LaSala (2003) describes, is a tendency to not notice the familiar. During the first I interviews I noticed that I tended to take for granted what the interlocutors told me and not asked enough follow-up questions. My tendency to 'not notice the familiar' as an insider might have played a role here, as the things participants told me sounded often familiar. However, not asking for clarification of answers does not only limit the depth in the interview, but also creates the risk of misinterpreting what the other says based on the personal experiences as an insider (ibid: 20). Therefore, after I became aware of this behavior I decided to ask more follow-up questions.

Structure of the thesis

In the three following chapters, I will present the stories of the women that I have interviewed for this research project. By presenting the stories of women, I aim to provide an overview of how different aspects of polycystic ovary syndrome are experienced by them. In most of the paragraphs, which are thematically organized, I have chosen to centralize the story or stories of one or more women. The stories are added by citations from other interviews where similar or rather contrasting statements are made. The most important reason behind the choice to present the stories holistically rather than only using isolated citations from the interviews, is to illustrate how the experience of PCOS symptoms, the encounters with biomedicine and self-care practices are related to each other in one person. As Arduser argues in relation to illness narratives, through these narratives it becomes clear how 'institutional and social forces interact with the individual experience of people living with illness in supporting and constraining agency' (Arduser 2014: 2). For understanding the choices that are made in relation to self-care, it is important to take the social and material context into account, and how the woman herself views the relationship between her environment, her behavior and her health.

Showing the illness narratives of the different women I interviewed, I hope to do justice to the diverse ways in which living with polycystic ovary syndrome is experienced and dealt with. However, as it is important to draw conclusions from these findings, I compare and contrast different experiences after analyzing a particular story.

In chapter 4, I will focus on the process of getting the diagnosis of PCOS by presenting the stories of three women in the study: Amber, Elisabeth and Emma. As 'diagnostic work is performative' (Moser 2010: 205), I analyze how the process of getting the diagnosis shapes women with PCOS in the perception of their self and their body, and how this influences their behavior. What preceded their diagnosis, and what does it mean for them to have this diagnosis? How did the diagnosis affect the way these women view themselves, their health and their future?

Chapter 5 will focus on the concrete experiences of women with PCOS in a number of areas: The effect of PCOS on appearance and the sense of femininity, the struggle with infertility, weight-loss, the management of physical pain and discomfort and the prevention of future risks. Each paragraph will start with a brief overview of the sample, after which the stories of one or more women will be highlighted. How do they experience these symptoms, and what does 'self-care' mean for them? What motivates them to engage in certain practices of self-care, and how do medical care and self-care relate to each other?

In chapter 6, I will assess the role of the internet as both a source of health-related information as well as a platform for fellow sufferers to exchange experiences and support each other. The chapter will start with a small analysis of self-care blogs and a facebook page related to PCOS, and will finish with a reflection of participants on the role of the internet in dealing with PCOS.

Chapter 4: Getting the diagnosis

'This was not how I perceived myself' – The story of Amber

Amber is a 19-years-old student at the University of Amsterdam. I met her as she responded to the advertisement I spread around the university campus. Amber was only diagnosed one month ago. As she tells:

> 'I stopped taking the birth control pills after the Summer, as I was taking it ever since I was fifteen years old. That was not a problem in itself, but I thought: I have been taking this for so long, maybe it is time to quit, as you also hear stories that it is not very healthy, and that people actually feel better when they stop taking it. And I had been taking it for so long so I thought: Alright, let's stop for a while, and see how that goes. And after that I had my period only once. Right now, I did not have a period in six months. So that was a bit weird. And then I thought: Well, my sister has it too, PCOS, so I went to the doctor who tested me and referred me to the gynecologist, who said: alright, we will test you. And then things went very quickly. She was very busy, it is that kind of gynecologist who sees a lot of people on one day, you know. So she did the ultrasound scan and then she was like 'yeah you really have it, very badly'. And I felt like 'ok'.. And then I left.'

Amber indicates that she found this consult 'a little weird' as everything happened so quickly and, looking back at it, she says she did not receive any further information about what polycystic ovary syndrome really is. Because of this, she called her general practitioner later on to learn more about it. She points out that she knew only very little about PCOS, except for what she knew from her sister. The fact that her sister has the condition contributed to her decision to get herself tested on it. Asking her about the symptoms she experiences, Amber points out that her loss of period is the main thing. This is not something she is really concerned about though, as she believes there are a lot of possibilities to restore this medically. Knowing that she has polycystic ovary syndrome, Amber indicates, also gives her the opportunity to take action whenever she has difficulties getting pregnant in the future. So in that respect, it is better that she already knows about it. In daily life, PCOS does not really affect her, she feels. However, she notices that there is an underbelly feeling in her that sometimes arises, and that she cannot really comes to terms with.

As she explains:

> 'When I heard that I had this, I was actually quite rational about it, because it is, it is actually not really a disease and you cannot feel bad about it, because it is, it is not really bad or something, I believed, but I remember that when I had it, I started to cry at some very

random moments, for example after I just got that diagnosis and that woman was pretty rude. And then suddenly I was outside on the street again and started to cry. Rationally I don't think it's a big deal, I mean, my sister has it as well, it is not really a problem, but it just wasn't how I perceived myself. I really had to get used to it, that suddenly, this was something that belonged to me.'

So, according to Amber, a 'rational' view on PCOS is not to see it as something severe, which she contrasts to an 'emotional' reaction of feeling bad about it. Saying that this was not 'the way she perceived herself', Amber means that before the diagnosis, she had the idea that everything was alright. The diagnosis with PCOS disrupted this idea and therefore changed how she perceived her own health. As she explains 'I also always had the feeling that I was very fertile. Not that I am not fertile right now, but it is still a bit different.' Moreover, Amber has never had any health issues, she says, so that is also why she feels it takes some time to get used to this.

Learning that she had PCOS, Amber started to think about herself and her own health in retrospect, especially in relation to her cravings for sugar which she has had all her life. Could this have anything to do with insulin resistance, which is often mentioned as a cause of PCOS? I asked her whether she changed anything in terms of her lifestyle after she got the diagnosis. Her answer is as follows:

'Well, I actually thought about that, when I read about that insulin, cause I have that, I really have an issue with sugar. But that actually has lessened right now, because I used to, well, I never really had an addiction to sugar or anything like that, but after dinner I always wanted to eat something sweet, and I can, I also feel that I can eat much more sweet stuff than my friends without getting sick. I don't really know if it has anything to do with it, but I immediately started thinking that when I read it. And I thought, I considered to stop eating sugar altogether for a while, just to see if that changes anything.'

Reading about PCOS and nutrition, Amber sometimes feels that she has to give it a try, especially as she read other success stories about it.

'Well I wanted to do that, because, well, they say that with the right nutrition you can manage it and some people even say that it completely went away by eating very healthy, I don't know if you have seen that, these 'vegan happiness' and 'vegan'… But well, I am never gonna manage to eat that healthy, so I – well I don't know if that is true – but yes, I wanted to do that, I don't eat unhealthy anyway I think, but it has not really changed since I know that I have that, no. I wanted to, but..'

So, Amber thinks that a specific diet could be useful for her based on the fact that some women with polycystic ovary syndrome benefit from this. However, the fact that 'she does not know if it is true' makes that the possible benefits of such a change in lifestyle do not outweigh the effort it would take to make such dietary adjustments. Amber further problematizes the uncertainty surrounding the cause of PCOS, stating that this can give people the feeling that they are to blame for it themselves. She has wondered sometimes whether her PCOS can be caused by eating unhealthy in the past.

> 'Yes, I think it can contribute to the feeling in people, for people who have it, it is sort of extra annoying that they get the feeling like 'ok, maybe it is something that I have done in the past…Maybe I could have prevented it' Because you just don't know where it comes from.'

Amber searched for information on the internet about polycystic ovary syndrome, but soon found that much of the information out there was not helpful to her and even scared her.

> 'There was so much information out there, that I thought like…That is also why I called my general practitioner, because, of course you can find a lot of info on the internet, but I just wanted to know from my GP what it is exactly, so that I don't.. Cause there is so much information out there, and then suddenly you start reading about uterine cancer or something, and then I thought, well, I don't think that needs to have anything to do with it necessarily. So then I prefer to hear it from my doctor.'

Amber perceives the opinion of her doctor as more reliable than the information she finds on the internet, and feels the risks that are mentioned on the internet in relation to PCOS are not always accurate. Therefore, she does not view the different discourses on PCOS and risk as equal; whereas the doctor's perception is backed by medical authority, the online information produced by lay individuals lacks this authority in her view. Being a lay individual herself, Amber doubts her own ability to accurately judge online health information as well. She wants to have certainty before taking steps to improve her health, and believes the doctor to provide that certainty. Given the fact that she is not having her period at the moment, Amber will start using the birth control pill again, as her general practitioner advised this for health reasons.

'Stuck in a body I can't control' – The story of Elisabeth

Elisabeth is a 26-year-old woman who is originally from the US, but has been living in Palestine for three years. She was diagnosed in the winter of 2010 after she experienced very bad acne and had an irregular cycle. She went to a gynecologist who referred her to an endocrinologist. The endocrinologist diagnosed her with a 'mild form' of PCOS after some testing. I asked her how she felt about the diagnosis.

> 'At first fine, so I was like 'Oh great', I actually was kind of relieved that I had a diagnosis and something was really wrong, at first I thought I was making too big of a deal out of something, it wasn't a real issue and I realized no, there are some medical reasons, so it, it felt really good actually.'

So for Elisabeth, becoming diagnosed with PCOS initially served as a confirmation of the problems she had. However, this initial sense of recognition soon changed:

> 'At the very first I was like 'ok great, there's a way forward', but after that I began getting really, it was, it was really hard for a while, I was diagnosed with PCOS and also mild insulin resistance, which is a one of the symptoms, one of the symptoms that can guide to PCOS, and I started to become very aware of my body, in an almost obsessive kind of way, and sort of any time that I saw, I had I had little tiny hairs on the top of my, of my lip and I thought they were getting darker, hairs on my arms and I felt really worried and I felt nervous and anxious and I thought I had more acne and so there's a lot of, how to say, more psychological symptoms associated with the idea, especially after I read it online I, I got what kind of felt like horror stories, people who were saying 'I've been trying for years to improve my symptoms and I can't, or I've been trying and no doctor listened to me and that wasn't my case, but it felt like: 'Oh, that could be me in time, if it gets worse and on top of it, what if no-one listens to me, what if I end stuck in a body that I can't control, right?''

By reading the stories of other women with PCOS online, Elisabeth got really anxious about her symptoms getting worse, especially when she thought to see real evidence of that. Besides that, she expresses her concerns about doctors not being willing and able to do anything, even up to the point where she will become 'stuck in a body' she cannot control. Moreover, it made her realize that even if she does not wish to conceive right now, this might become difficult in the future as a result of her diagnosis.

> 'And so I got pretty down and then it started to get better, I started metformin, and glucophage, I think is another name for it, to treat the insulin resistance.. And that was great,

> because all of a sudden I, I looked better and that really affected how I felt, to be totally honest, I mean it might sound a little depressing, but having the physical symptoms somewhat alleviated helped me to feel like it was not a death sentence kind of a diagnosis, I met other people who have it, and we talked about it, kind of by coincidence, but after you know six months or so I started to feel really good, but it took a little while to…get settled.'

Elisabeth got prescribed medication to deal with the consequences of insulin resistance - metformin and glucophage – which affected her appearance in the sense that it clear up her acne, and as a result, she also felt better and her initial anxiety withered away. Elisabeth got *settled*.

'To know what causes things' – The story of Emma

Emma is 24 years old and works as a trainee in The Hague. A year ago, she stopped using the birth control pill, which she started using as a teenager. Back then, she used anti-acne medication that she was only allowed to take on the condition that she would take the birth control pill as well, because the anti-acne medication could be harmful to an unborn child in case she would get pregnant. The pill was practical as contraception too though, as Emma has been in a relationship ever since age seventeen. However, a year ago she got 'tired of the pill' and wondered what it would be like if she would stop taking it. After half a year of not getting her period back, Emma visited her general practitioner who initially did not suspect anything to be wrong, but still referred her to a gynecologist. The gynecologist diagnosed her based on an ultrasound scan.

> 'And since then, I knew it, alright, PCOS, so I started looking up information about it, what it is and what I can do about it, and my general practitioner only said 'PCOS is not that bad as such, it only means that if you want to have children, that can be a tough process'. Then she asked if I was overweight – we had a phone call – and I said no, and then she said 'Oh, well, then there is nothing you can do about it'. So that was it.'

In Emma's account, the general practitioner qualified PCOS as 'not bad', based on the fact that it will not have any health consequences on the short term. Instead, she perceived the symptoms of PCOS to be impactful only at the time a woman would like to become pregnant. Given the fact that Emma did not have a period, the general practitioner advised her to start taking the birth control pill again. However, Emma was not satisfied with that advice:

> 'I thought: Yes, but I don't want that, because I think it is because of the birth control pill that I got these problems in the first place. Well, I might have genetic predisposition for it as well, because I had acne before I started taking the pill as well, but then I went out to look for

> information about it myself to see how I, yeah, can control it, with things like eating low-carb, no sugar, and now at least I manage to calm down my skin.'

Despite her belief that genetic predisposition plays a role in the development of her acne, Emma feels that it is something she can also control herself, at least in part. She has found what she sees an underlying cause of her problems: insulin resistance. She learned about the existence of insulin resistance when visiting a herbal supplement store, and spoke to the woman working there. They talked about her symptoms, and the women working in the store asked her if she often feels faint and has cravings for sugar. Emma realized that this was the case, and feels that she might be insulin resistant:

> 'That is another symptom of your body, that is does not process insulin well, keeping your blood sugar stable, and that can, as I have understood, also deregulate your hormones, so if you keep that calm, you can regulate your body. I notice, yeah, that if I work on that, if I carefully watch my diet, that my skin clears up as well.'

And so, Emma started to eat low carb. For example, she has replaced the slices of bread she used to eat during the afternoon for snacks with vegetables or lentils. In addition, she started eating full grain pasta and quitted eating candy. However, she tells that she has to be careful not to lose too much weight because of this, but she knows how to manage that. Emma still does not have her period back. This is not something she worries about right now, and instead tries to focus on sticking to her lifestyle adjustments in the hope this will also restore her menstrual cycle in the end. She indicates that in general, knowing where her symptoms come from and being able to do something about it, makes her feel confident: 'I think that if the diagnosis of PCOS affects my self-esteem, I think it is mainly in a good way. That I know what causes things. That it gives you self-esteem, that you can have some control over it.'

However, lately Emma came to realize that her lack of menstrual cycle affects her more than she initially thought. She does 'role playing', which is a form of theatre. Recently, she had to play an infertile woman. Emma says that this had quite an impact on her, and made her realize that unconsciously it does more to her than she thinks.

Conclusion

Through presenting three illness stories, I gave an overview of the way getting diagnosed with PCOS affects the life of a PCOS sufferer. As these stories make clear, the process of getting the diagnosis implies more than just a determination of what is going on inside the woman's body. Whereas the women visited the doctor not knowing what was going on and if they even had a health issue, they walked out of the doctor's office as PCOS sufferers. This shaped the subjectivity of the women in many different ways: how they perceive their bodies, how they view past and current health issues, their fertility, their femininity, their future and their agency. However, from the three accounts, it becomes clear that this happens in multiple, somewhat contradictory ways.

Whereas in the situation of Amber the diagnosis took place in a situation in which she did not perceive her body as if there was anything not right prior to the diagnosis, for Elisabeth the diagnosis came as confirmation of the symptoms she had. The diagnosis also shaped their perception of agency in different ways.

On the one hand, especially in the situation of Emma, it gave a feeling of control over the situation: Now that she knew what has caused her problems, she could do something about them. To a lesser extent, this also figured in Amber's story as she described that knowing about her diagnosis gave her the option to seek early intervention in case she would have problems with fertility in the future. Whereas the diagnosis initially gave Elisabeth the feeling that she had lost all control over her body, she gained the sense of control back eventually as she managed to get grip on her symptoms.

However, as becomes clear from all three stories, the act of getting the diagnosis also produces a feeling of uncertainty about the future that was not there prior to the diagnosis. The uncertainty is mostly related to pregnancy in the future. However, the 'risk' of infertility is estimated differently in the different stories, and Emma is not sure if she even wishes to have children. This uncertainty also plays a role when it comes to trying to uncover a cause of polycystic ovary syndrome and whether this can be attributed to their own behavior.

Finally, the women differ in their care-seeking behavior. Emma and Amber encounter the same two discourses on polycystic ovary syndrome: The one that was produced by their physicians – that the restoration of the menstrual cycle should be a priority, and should be established with birth control - and the discourse in which diet is promoted as a way to balance their hormones. However, Emma and Amber evaluate these discourses differently, and make different choices on whether to go on the birth control pill or to adjust lifestyle. Elisabeth managed to balance her symptoms through both prescribed medications and lifestyle adjustments.

Chapter 5: Dealing with PCOS in everyday life: On treatments and self-care

PCOS, beauty and femininity

Nearly all respondents stated that PCOS influences their appearance in some way. In most cases this was related to the condition of their skin, the presence of excess facial and body hair or thinning out on their scalp. Another important way in which PCOS influences the appearance is because of its impact on body weight, which will be discussed later on in this chapter. Participants differed in the extent to which they ascribed these factors to PCOS, and whether they had the capacity to do something about it. Below I will highlight the stories of two women: Nadine and Ayse.

Nadine

Nadine is 33 years old and works as a consultant. She was diagnosed with polycystic ovary syndrome two and a half years ago, as she did not get her menstrual cycle back after stopping the birth control pill. The diagnosis came as a shock to Nadine. Although she was not actively trying to conceive at that time, she came to realize that getting pregnant could be harder than she expected, or maybe would not even be possible at all. Because of this diagnosis and her age, Nadine and her partner are now considering trying to conceive. However, Nadine is hesitant to start actively trying to conceive immediately. She fears that the disappointment for her and her partner will be immense if it does not succeed**.**

As she tells:

> ‘I find that scary, if I would go for it for the full 100% and say: I want to have a child, and that does not work out.. Then it feels as if the wonderful life we have right now is not worth it anymore, or so. Then that is not good enough anymore, while actually, I am quite happy with my life as it is right now. So I want to keep it that way.’

As a way in between, the first step in this process will be the removal of her intra-uterine device coming Summer, to see if she will become pregnant spontaneously. If that does not work, she might consider starting hormonal treatment.

In relation to her PCOS, Nadine started following a low-carb diet a while ago with the help of a nutritionist that is specialized in hormonal issues. The diet, as she explains, mainly implies that she should try to eat ‘slow carbs’ and should supplement them with proteins. Besides that, it is important to eat regularly, every three hours, to keep blood sugar levels stable.

Nadine says she has been struggling with irregular blood sugars all her life and, as a result of this, she used to have a very strong urge to eat sugar rich foods in the past. With the diagnosis of PCOS, she started to wonder if the irregular blood sugar levels could be part of the syndrome. If this would be the case, the low-carb diet could also help promote her fertility by balancing her hormones. But as Nadine points out, it is far from certain that this diet will actually have any impact. After all, different health-care professionals Nadine consulted say different things about this. Whereas the nutritionist told her that she might be insulin resistant and therefore benefit from a low-carb diet, a gynecologist she went to thought her nutrition has nothing to do with it. As she describes the uncertainty this brings about:

> 'I always find it very difficult if nutritionists pretend: 'we're gonna put you on a diet and then it will be all gone, that is of course, you really need to relativize that, cause it is just not true.. On the other hand, it really helped me because it helped to be in balance in terms of blood sugar levels, to have more energy and that kind of things.. that is what I got out of it, so, I am very happy that I went there. But ok, the fact that I have issues with my blood sugar levels in itself does not need to have anything to do with PCOS. Because they say everywhere: Yeah, PCOS goes hand in hand with insulin resistance, but yeah, it also goes hand in hand with overweight, and I never had that. And yeah, nothing is proven. I went to two different gynecologists and they said totally different things. 'Oh yeah, having children, nothing to worry about, just come back whenever you're ready for it, whereas the other said like, if you want that, you really need to start thinking about it, cause the older you get, the harder.. et cetera. So yeah, I really don't know what helps, what not, what is related to PCOS, what not.'

Despite all the uncertainty related to its working, the main direct benefit of this diet is that is it helps her to stabilize her blood sugar levels and to prevent her from having food cravings. Nadine feels that the diet is very helpful in that sense. Following her nutritionists' advice, Nadine also started taking a nutritional supplement called 'Stress B Complex'. Her boyfriend, who is a physician, is very sceptic about this and said, jokingly: 'That is also what we give to drug addicts!'. Nadine herself too is far from certain that it helps, but says:

> 'But in some way, yes, sometimes it just helps to have the idea that you're doing something about it. And then you think, yeah you know, why not spend a bunch money and just see if it works.'

Besides the absence of her menstrual cycle, Nadine mentions excess facial hair as a symptom of her PCOS, and considers this to be the most influential PCOS symptom for her at the moment.

Looking back, she thinks that her facial hair has gotten worse already since she was halfway her twenties. But especially when getting off the birth control pill, Nadine feels that the hair growth increased rapidly. She used to remove the hairs herself by plucking and shaving them. However, as she sometimes ended up with a graze on her face, she decided to go to a beauty therapist instead. She visits the beauty therapist once in every three weeks and has the hairs on her face removed. With her visits to the beauty therapist, Nadine feels that she can manage the hair growth. However, the fact that she 'has' to go there regularly, is somewhat burdensome as it takes a lot of time and money. Because of the impact of the facial hair, Nadine has considered to have the hairs removed permanently by hair laser removal therapy. However, as she was not sure about how many treatments she would need and if it would even work at all, she decided that it is not worth spending a lot of money on right now.

The facial hair has a large impact on her self-esteem. As Nadine tells:

> 'Well, it just makes you very insecure. So small hairs appeared on my upper lip, and then sometimes you have something on your cheeks and you think: 'No, I don't want this! This is not supposed to be there!' It just makes you feel very insecure and at first, I did not really know how to deal with that. Well, if you see a tiny little hair once and you pull it out, you think, 'Ok, everyone has that every now and then', but especially that hair on my upper lip and chin is like that I thought… I don't want this, this.. This makes me less feminine, and that makes me feel insecure. Insecure about who I am and what people see when they look at me, and what my boyfriend feels when he touches my face and that makes me feel so insecure, so you really have to find a way in that.'

As Nadine tells, the hairs on her upper lip make her feel less feminine as she feels they are 'not normal' for a woman. Whereas she considers have a single hair on your face as normal – 'everyone has that' - , having more than that and having hairs on the upper lip and chin, she no longer perceives as normal for a woman, and therefore it becomes problematic. Nadine points out that she changed this view in order to accept the fact that she has to remove facial hair:

> 'Yes, I think in terms of acceptance, at a certain point I took the step to realize that removing facial hair is actually no different from shaving your legs, which every woman does. I think that if you reach that point, and think like, 'ok, this is just one of the many things that I have to do in order to meet the requirements of femininity', in a certain way that was for me the moment that I could deal with it again, that at least in relation to my own femininity, I had less difficulties with it, I thought 'Ok, this is just a thing, it is just… A human body has hairs, in

some way it helped me to realize this. In a certain way, I also think that I put more effort into dressing up more feminine, or wearing more jewelry, whereas years ago, then I was only wearing make-up if I went somewhere, to an important event, and at a certain moment that changed into: if I have to go to my work, and now it's actually more like that I only do not wear make-up if I know that I..if I have to go swimming or jogging, then I don't wear it, but yeah, I really changed in that sense.'

In her account, Nadine presents shaving legs as an ordinary female grooming practice, whereas she initially thought that removing facial hair was not. By changing her view and coming to see facial hair removal as a similar thing and therefore 'just as normal', she re-conceptualized her notion of normal feminine beauty practices. As a result, the fact that she has to remove her facial hair becomes more acceptable for her. Wearing more make-up and jewelry than before she had excess facial hair, she compensates for her feeling of being unfeminine by performing femininity in different ways. This also relates to her body shape, which she does not perceive as very feminine:

'Well, yes, maybe that I feel a stronger need towards myself, to feel like: Yes, I am actually a feminine person. There are a lot of factors, because from a very young age already I felt that I am quite muscled, that is just my body type, even before I started exercising… And that made me doubt myself, that I don't have that thin, petit body you see on the covers of the magazines. But that you are actually a woman, and you want to be seen that way.'

From all of these statements it becomes clear that Nadine has a strong wish to be and look feminine. However, she struggles to fully attain the standards of normative femininity, at least in her own perception. Nadine points out that her experiences with polycystic ovary syndrome have made her much more aware about her own perceptions about femininity. She describes that in relation to a story that spread around the internet a couple of years ago, about a British woman with PCOS who consciously decided to let her chin hair grow and has a full beard[2]. As she describes:

'Although I wished I would be noble enough to be happy for her and think it's amazing, I actually thought it was very unpleasant to see, I thought: I would never ever do that. So I thought that was quite typical for myself: Then I think like, yeah, the society you're living in and in which there is a certain standard, yeah, that does have an impact on you. And no, it is not as if this is something I think about daily, but in such moments I realize that, and I think yeah, this definitely impacts my own norms and values.'

[2]http://www.dailymail.co.uk/news/article-2718806/It-makes-feel-like-confident-woman-not-afraid-break-society-s-norms-British-bearded-lady-new-photography-exhibition-showcasing-world-s-best-facial-hair.html

Elisabeth made a similar argument, surprisingly relating to the same story about this woman:

> 'Beautiful, but to be totally honest with you and this is something I hope nobody... I don't know, I judge myself a lot for thinking in this way, but I completely am terrified, that if that happens to me, I don't know what I would do. I would do a massive laser, I'm not sure, like I would do hormone therapy, something. Like her level of self-acceptance is incredible to me. Because I think it's just never ok in any part of society. Not only does it break what it means to be a woman, according to society, but it breaks the idea of gender even because it's the facial features of a man but in a woman.. But I would, if I were her, I'm sure I would fear and very much internalize what, because I feel somewhat a man and a woman, I hate that of myself, but I really do and..I still feel like if that ever happens to me I would really…it would completely bad, it would be very bad. I would like not accept it…'

Her experiences with PCOS have challenged Elisabeth in her perceptions of herself as someone who does not adhere too much to gender norms, and made her realize how conscious she is about them, something she strongly dislikes about herself.

Ayse

Ayse is a Turkish-Dutch 34 years old woman and a mother of two young sons, who are crawling around her when we have our Skype interview**.** Her trajectory towards pregnancy, she describes as 'a very long and complicated road' and went in and out of hospital, as she says. Eventually, she conceived with the help of in vitro fertilization. Ayse was diagnosed with PCOS at age sixteen. Before that, she has never had her period. Her mother was concerned because of this and took her to the general practitioner, who referred her to a gynecologist. The gynecologist made an echo and diagnosed her. As her main symptoms, Ayse described that she has very bad acne, and has large fluctuations in her body weight. Besides that, Ayse struggles with immense hair fall as well as excess facial hair. Because of her hair fall, she wears a hairpiece, to cover up the bald spots on her head.

Because of the spots and hole on her skin resulting from her acne, she wears a lot of make-up, and tells me that she does not dare to leave the house without make-up on. Recently, she has started light therapy for her skin, but does not notice major differences yet. She also recently started using a filler for her skin. Ayse often feels embarrassed because of her skin problems. But besides this, she mentions that she also gets remarks about this regularly. 'Why are you wearing so much make-up? Why do you have these holes in your skin?', these are questions that people would ask her. Only little people in her environment know about her PCOS diagnosis.

As a result of her skin problems, Ayse has an extensive daily facial care regimen. She cleans her face with a scrub, and applies a serum in combination with the filler afterwards. In addition, she shaves her face twice a day, to be sure her skin remains smooth and hairless. She is very conscious about this. As she tells:

> 'I work in shifts, and sometimes, at noon I already notice that the hairs are growing back. And then I would run to the mirror, and put some make-up on my face. To cover up the dark spots. Yes, that is really annoying.'

If I ask her why she is so conscious about this, she explains: 'It shouldn't be. A woman should, at least…You just don't see it.' Besides the use of make-up to cover up facial hair and acne, Ayse also indicates that she also just feels more 'feminine' with make-up on. Just like Nadine, she relates this to her body type, and her make-up use compensates for this:

'I just have, how to say that, naturally I have kind of a masculine expression, I think. And maybe that is also because I know, that I have excess facial hair. And I hardly have any breast, that also has to do with it.'

Because of her little breasts, Ayse has considered plastic surgery in the past, and still does. 'I always think, you can make every woman the way you want; with a hair piece, with make-up, by filling up her breasts…' However, the high costs prevent her from undergoing plastic surgery at the moment.

Like many other participants, Ayse also follows a low-carb diet, which helped her to lose thirty kilograms, as well as restored her menstrual cycle. In addition, as she tells about the effects of the diet:

> 'I feel much fitter because of it. I used to be always so tired, did not have any energy.. Right now, I feel much fitter. I simply feel better.'

Moreover, Ayse takes vitamin D and magnesium supplements on the advice of her doctor, as she had deficiencies in both.

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Both Ayse and Nadine describe a feeling of being less feminine as a result of different kind of PCOS symptoms, such as facial hair, acne and hair fall, and contrast these features in their body to normal femininity. They deal with this through removing the excess hair, hiding symptoms and compensating for their feeling of being unfeminine, for example through the use of make-up, or, as Nadine does, through clothing and jewelry. Doing so, they consciously perform femininity in different ways. Both women have adjusted their lifestyles as well. Ayse seems to view her PCOS symptoms as manageable

in some respects following from her diet. She tells that she has been capable of losing weight and restore her period through her own behavior. Compared to Nadine, she is more certain that these differences can be ascribed to the lifestyle changes she made, and therefore grants herself more agency in affecting these issues. Nadine is much less certain about this, as she points out that the information on her lifestyle changes lacks clinical evidence. She believes that adjusting her diet indirectly could have an impact on the hair growth by balancing her hormones. However, she is not sure about this. This does not prevent her from engaging in these practices, as it provides her with the feeling that at least she is trying something to influence it. Finally, Nadine deals with the consequences of excess facial hair by changing her mindset about it. By perceiving the removal of excess facial hair as an ordinary feminine beauty practice, it is poses less of a challenge to her understanding of normal femininity, and therefore becomes more acceptable.

Fertility treatment

Fertility as a topic figured in all of the interviews, but the participants related to this topic in different ways. Some women were actively trying to conceive (n=4), with the use of hormonal treatment or in vitro fertilization, others were trying to become pregnant spontaneously without any intervention (n=2). Another group of participants indicated that they were not trying to conceive at the moment, but had concerns about how this might work out in the future (n=7), and 1 woman stated that they did not want to have children at all. Three women were mothers, but had a complicated trajectory towards getting pregnant in the past, in which they were not sure if they would ever succeed. None of the women I had interviewed had unsuccessfully been trying to conceive in the past, but had given up trying. Forms of non-prescribed self-care related to improving fertility included dietary adjustments and supplement use, including herbal supplements such as Maca root or vitamins such as ‘Stress B complex’.

To give insight into the fertility struggle of women with PCOS, below I will present the stories of three women: Joyce, Anna and Hayley.

Joyce

Joyce is a 22-year old woman who I met through the Facebook group PCOS Nederland-België, in which she is very active. Joyce was diagnosed with PCOS about a year ago as she did not manage to get pregnant. When she first heard about it, Joyce did not think PCOS would be a big issue in getting pregnant, but this changed after a while:

> 'Well, I just thought 'ok, so apparently there is something, and there are medications that will solve that, so within now and half a year we will have a child, or I mean, be pregnant with a child. So actually I took it really light when I first heard about it. It was quite a slap in my face, like ok, well, so apparently there IS something wrong with me.. And that did not feel fair. But two, three cycles after, it really impacts you, and only then you will notice, it is not as easy as it appears, and it is really intensive. I thought too easy about that.'

Since then, Joyce describes how she has hope every month, which often results in disappointment. Since she got the diagnosis, she has been taking Clomid, a medicine to promote fertility. Besides the use of Clomid, Joyce is trying to lose weight and watch her carb-intake as a way to promote fertility. As a result of the PCOS, Joyce has gained over thirty kilograms , which she now tries to get rid of with the help of a nutritionist.

As she tells about her current treatment regimen and the impact it has on her life:

> 'You have a schedule you need to stick to every day, I have a diet, every day I need to eat exactly the same things, there is some variation in it of course.. In terms of tastes and that kind of things, but it is actually the same every day. Taking medications, it has a lot of side effects for me, a lot of bad things such as hot flashes, mood swings and that kind of stuff, so that is the extra layer to it. And the constant disappointment 'Ah, I'm having my period this month again, it did not work out..' So, yes, it affects me every day.'

Besides her diet, Joyce takes folium acid to promote the health of a future baby, and medications to stimulate her thyroid function, as she struggles with hypothyroidism. If I ask Joyce how PCOS impacts her the most, she points out that it is the emotional aspect. Especially, in the beginning of her treatment, Joyce has moments in which she did not see any hope any more and wanted to give up trying. As she describes:

> 'Yes, I had a while, especially in the beginning, that I felt like: Alright, leave it, it is never going to work, I will never have children, that you go through deep valleys, but in the end you will get out stronger and it is, it helped me to talk about it with people, with a very intimate group of people, who stand close to you, and they pull you out of that negativity.'

Especially, the social support of her boyfriend and her mother is very important in dealing with the 'emotional rollercoaster' Joyce finds herself in. While she and her boyfriend had a time in which the fertility issues and Joyce' hormonal imbalances put pressure on their relationship, they realized this in time and managed to solve it, Joyce tells me. Now she can talk with him about how she feels. As she tells:

> 'Yeah, so my boyfriend and me, we are very open towards each other, we talk a lot with each other, so yeah he works every day.. and he gets home and then I have such an off day, then he comes home and he says: 'Hey, how was your day? And then I start crying and he already sees that there is something wrong, and then we talk about it and I say: 'I'm done with it!' And: 'Why can't I have children, what have I done wrong?' Such things, well, we talk about it, and, with my mother I talk about it as well, but she does not fully understand it, because she is not so close to the situation as my boyfriend and I. And she, she is like, if I say things like 'I don't feel like a proper woman because I cannot have children', she would say things like, 'But why are you any less of a woman? And who says you can't have children? You do everything you can, right, in order to have kids?' And she turns it into something positive, like, by saying 'You're so strong that you take all these steps, and you don't give up.''

As becomes clear from the citations above, Joyce sees the emotional burden of struggling with infertility, which is reinforced by the side effects of fertility treatment, as one of the most important ways in which polycystic ovary syndrome affect her life. Her environment plays a role in motivating her by challenging her negative thoughts. This helps her to stick to her regimen and to stay positive. Therefore, next to following a diet and taking medications, talking about her feelings can in itself be a form of self-care for Joyce.

Anna

Anna is a 30-year old married woman who only got the diagnosis of PCOS a month ago. She got married almost a year ago, after which she and her husband decided to try to have children. As she says, the diagnosis did not make her desperate about her chances to become pregnant, but she did realize it would become harder for them.

At the moment, Anna tries to conceive 'naturally', with which she means without hormonal stimulation. During the last two months she ovulated, which makes her hopeful about her chances to conceive this way. Anna closely monitors her ovulation, and knows exactly when she is fertile. Despite the fact that she does not receive any regular medications, she is consulting a natural doctor who prescribed her a range of supplements and alternative medications for different issues. Initially, she visited the natural doctor because of her asthma. However, as she appeared to have hormonal issues, she wanted to work on these issues as well with the help of that doctor. Anna stresses that she prefers a 'natural' treatment over hormonal therapy. This, in part, has to do with the fact that she fears the side effects of medications such as Clomid. Therefore, she takes a whole range of

alternative medications: Serotosan ('for my mood, and it also has to do with hormones, just to relax my body and mind'), Silibum ('supports my gallbladder'), stress B complex (Stimulates hormones, but also for my asthma'), Omega 3 acid, and cimicifuga drops, which the natural doctor prescribed her. Besides that, Anna sometimes takes Passiflora complex (an alternative medication) or magnesium when she has a painful period.

Anna says that the hardest moments to deal with, are when she is confronted with her fertility struggle, because other people in her environment become pregnant or have children. A common moment of these confrontations is when children get baptized at church, which she and her husband visit every week. Other confrontational moments are when people ask her about if they plan to have children, now that they got married. She has not told many people about PCOS yet, and only plans to do so if she would start hormonal treatment. In part this is because of fear of not being understood, but also because she feels somewhat embarrassed because of it. Anna points out that her struggle with fertility issues sometimes makes her feel less feminine. As she explains:

> 'As I said to my husband yesterday, it does affect your sense of femininity. So in that way, it can make you feel less self-confident. Yesterday, we went to church and the sermon was about marriage, a topic that really appeals to us. And then it was said that having children is a blessing. And then it was like, ok, but if we can't have any children, does that make our marriage incomplete? So yeah, rationally I know that it makes no sense to think like that, because of course our marriage can be just as good. But still, that question comes to your mind, so yeah, it does affect your sense of certainty, or your self-image, yeah. '

Hayley

Hayley is a married woman who has a seven-years-old daughter. When her daughter was two years old, she and her husband tried to have a second child, and they have been trying for the past five years. Hayley tells me that she has tried a lot of different remedies. Her first daughter was conceived after a year of hormonal treatment, but this time, her body did not respond to Clomid anymore.

When Clomid did not work, Hayley started trying more 'natural' remedies, including supplements such as Maca, L-arginine, and Vitex. But, as she says, 'I actually need to go to a homeopathic doctor before I continue, because it, I don't really know what helped, sometimes it did give me a cycle, but sometimes not'. Besides the use of supplements, Hayley is really conscious about the hormone disrupters in body care products, and tries to avoid certain chemicals ('xeno-estrogens') as much as she can. This is hard though, as the chemicals she tries to avoid are in many products, as she tells me.

Besides that, Hayley is strictly watching her diet, eating low-carb. She points out that the reason for her to stick to this diet is not because she is overweight, but because she has a tendency to gain weight around her torso. And especially over there, it poses a risk of developing diabetes, she points out. Moreover, she hopes that her low-carb diet will promote ovulation, but is not sure that it will work that way.

Whereas Hayley described her experiences with doctors in the past quite negatively –'they did not monitor my symptoms, I was just put on Clomid'– she points out that she has a very good doctor now who 'supports me if I come up with myself, and is willing to investigate that with me'. This is something she, as well as other participants, mentioned as important during the interviews: that doctors are open to their own suggestions on remedies that they have found out about.

During the interview, Hayley is not actively trying to conceive anymore. As she explains:

> 'It was just very tough on me. Physically, financially, and all the doctors appointments.. At some time I might get back, but we decided to spend our money to take our daughter on vacation rather.'

However, she and her husband still hope for a 'miracle', she says. Hayley tells that when she first heard she had PCOS – which was before the birth of her daughter- , she was very pessimistic about her chances to ever become pregnant. 'When I first heard that I had it, I was pretty broken. I looked on the internet, and read stories of women who did not succeed, and that really scared me.'

She started her own blog on PCOS five years ago to describe her own fertility struggles, which grew out over the years and has become very popular. Through her blog, she also had real-life encounters with other women with PCOS. As she describes this process and the purposes of her blog:

> 'The pastor at church encouraged me to [start it]. Because he knew I was a writer, and it became very therapeutic to just be honest and say 'hey, I'm feeling this, I want to put this out there, somebody might relate, and it surprises me that the posts that are really popular, it's not what I expect to receive, you know. I don't receive hateful comments, I receive way more support, and that's been great. I'm honest about how it makes me feel at times, how it affects my daughter, a lot of times I share like things that I tried, and you know to be healthier whether it's new herbs, a new vitamin or something that I have discovered, or just natural ways to try to keep symptoms away, and then I've also tried to create space for women who've come through similar pregnancy issues like me, because my pregnancy was a very high risk, I had a rare condition during mine, and so it's one that takes a lot of baby's lives, and a lot of women's lives, and so I've created a space on the blog for success stories

> or women to share their way if someone is looking up that same condition, they're not just gonna find all the kind of things I found on the internet. That scared me to death, you know. They got success stories, so I tried to do things like that too.'

So, Hayley's own experiences of being discouraged by online stories of other women unsuccessful pregnancy struggles motivated her to provide space for the motivational stories consciously, hoping to give motivation to other women this way.

Shortly after the interview, I got a message from Hayley. She experienced another 'miracle': While she was not trying anymore, she got pregnant with a second child.

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The three accounts make clear that the struggle with fertility issues is experienced as very emotionally burdensome, in which hope and despair alternate each other. Moreover, women can feel abnormal, embarrassed and unfeminine because of it. Both Joyce and Anna contrasted their fertility problems to normal womanhood. Moreover, Anna is afraid that her environment perceives it that way too, and, as a result prefers to remain silent about it. For Joyce and Hayley, however, talking or blogging about the situation and their emotions is relieving, and a way to keep themselves motivated. At the time of the interview, all three women indicated that they felt uncertain about if they would ever become pregnant. However, despite limited hope they actively try or had tried to influence this process, mainly through adjustments in lifestyle. Interestingly, both Hayley and Anna make a distinction between natural and non-natural treatments and point out that the prefer 'natural' methods. Whereas for Anna this was a conscious choice from the beginning, Hayley did so because she did not manage to conceive with prescribed medication.

Losing weight

Four participants are actively trying to lose weight. The motivations provided for the weight loss included concerns for future health risks (mostly related to cardiovascular diseases and/or diabetes), the stabilization of blood sugar levels, the improvement of fertility, increased self-confidence and emotional well-being, and, simply the wish to look thinner. Often, it was a combination of two or more of these factors that the women mentioned as motives for their weight loss. While two of the women could not be classified as 'overweight' according to medical standards, they felt that lowering their fat percentage or body weight could lessen their PCOS symptoms.

Grace

Grace is an American woman in her twenties, who works as a health biologist. As she tells me, her PCOS symptoms started at age fourteen. At that time, all of a sudden her period stopped. Around the same time as losing her period, Grace gained around thirty pounds, while she said she has been thin all her life. Only when she was in college she found out that she Hashimoto's disease as well, a disease that causes hypothyroidism. At the time she was diagnosed with PCOS, the doctors prescribed her the birth control pill, and advised her to take more exercise and eat healthy. However, Grace already did a lot of exercise and ate healthy, so she felt frustrated with that advice.

The birth control pill brought back her periods. Later, Grace also started with metformin, a prescribed medication that stabilizes blood sugar levels. However, this medication made her feel very nauseous. After she switched to another birth control pill, which contained anti-androgenic components, she noticed that some of her symptoms got better. For example, her skin cleared up, and the hair growth on her arms, although it has never been so bad, decreased.

Grace points out that her weight is still an issue, although she did manage to lose a lot of weight. The challenge for her now is to maintain a 'healthy weight'. For a long time, Grace has been frustrated about the fact that everything she tried to lose weight, whether it was the metformin, diets or different exercise routines, did not seem to help.

> 'I almost felt like it was pointless, because you tried so hard and it's like: Why? And then people would tell me like just diet and exercise and I'll be like: 'But you don't understand, I diet and exercise more than everyone.. and it's not working. So it's like, it's so frustrating''

In the end, after long searching Grace found out about a form of workout that really worked for her: 'High intensity interval training'. This workout, which she learned about through the website www.fitnessblender.com, implies that you work out intensively for a short amount of time, and then rest, in intervals. According to Grace, this speeds up your metabolism and improves insulin sensitivity. On this website she read about the main structure, but tried out for herself which exercises she liked and which she did not like.

Also in terms of diet she has tried many different things, and found out about a 'ketogenic' diet, which worked for her. The diet implies eating 'no carbs, no sugars and no glutes'. According to her, there is 'a lot of research' on how this diet relieves PCOS symptoms. Although she experienced clear benefits which she ascribed to that diet – her bloating went away, skin improved and her belly

flattened – it was hard to maintain, especially socially. She could not eat out with friends anymore. For this reason, she became a little less strict in her regimen now.

Grace tells that she got her information about the diet mainly through the internet. Although Grace managed to find an exercise and dietary regimen that worked, she described her search for a successful weight-loss strategy as very tiring. For a long time, she has felt very uncertain about what works and what does not. The fact that she does not want other women to go through the same struggle informed her decision to start her own blog about PCOS management.

> ‘At the time of my diagnosis there was no information. Now there is a lot of information, but what is correct, what is reliable? And a lot of the information out there is kind of similar in nature I find, and I keep reading the same things over and over again. So it’s like, it’s great that there’s so much information out there, but at the end of the day, if you keep reading the same things when you’re looking for things, for me that’s kind of frustrating, because if I want to find something, I want to find something new. Because, it’s kind of like that thing that I was saying earlier, like when you’re exhausted of options, you still like to have that hope to know like ‘I’m gonna try something new and what is that thing gonna be?’ So that is kind of I guess the purpose [of my blog] in some ways, it’s also I think in a way for me because I struggled with a lot of these things for so long, until like getting it out is.. is good, and knowing that it is like all the, the struggles that I went through, like other people have been through, like I don’t want other people to go through that like, because I went through them, so maybe I can help them. That makes me feel better. And just saying that I know how painful of a journey it is and I don’t want other people to have to go through that, you know. So, that’s my hope’.

On her blog, Grace provides many advices about lifestyle and PCOS. According to her, you can impact your own body through lifestyle, as she managed to do herself, but you have to find the right information. Although she feels that much of the information online ‘lacks clinical evidence’, on her own page she is very conscious about scientifically backing up the advice she provides to readers.

Managing pain and physical discomfort

A few participants struggled with pain and physical discomfort as a result of PCOS.

Laura

Laura is 26-year old Chilean woman who studies economics at the University of Amsterdam. She was diagnosed with PCOS because she had very irregular and painful cycles, preventing her from doing her daily tasks. As a result of this, she ended up in hospital a few times, and had surgery on her ovaries to remove the cysts. Laura was already quite familiar with PCOS when she got the diagnosis. All of her female family members have something on the ovaries, she says, as well as many of her friends. The doctor prescribed her the birth control pill, but Laura faced very heavy side effects. In the end, she tried out five different pills because of this. Right now, she is not taking the birth control pill anymore because she could not find the same pills here in The Netherlands as in Chili.

Unlike many other participants, Laura mentions the pain resulting from growing cysts as the most impactful symptom of PCOS. As she tells me about one of the first days in the Netherlands:

> ‘It was in the first days, I felt really miserable. So then I just stayed in bed. So I kind of skipped a lot of uni.. that day, I just only came for the class and then rushed back home.. I used to take a lot of anti-inflammatory pills, maybe taking three or four, still not enough, but I'm not.. I don't like taking more than that, I used to three of four like pain killers in one day.'

The heavy pain she experiences comes and goes, often quite unexpectedly. She deals with this by taking a lot of pain killers.

Although she says that her pain is manageable at the moment, Laura strongly feels that she should see a doctor soon, to have her ovaries checked, as the cysts are growing constantly. She used to do this in Chili every year. However, she did not manage to find a good doctor here in The Netherlands, and her student insurance does not cover everything. Therefore, she only wants to go in case of emergency or when her symptoms really get worse. As a result, she is not receiving any medical care right now. Throughout the interview, Laura mentioned several times that having polycystic ovaries is something very common in Chili.

> ‘I think like half of my friends in Chili have this like, it's pretty common. You're complaining about the pain, or you're like ok like.. referring your gynecologist ‘Which one do you have that is actually good?' or something like that, and you go to a different city and you call your friends ‘Ok, which one are you going to?' Because I need one here. Or which pills are you

taking, it’s something really common because we all have it. I mean, at least half of us have it.’

Laura felt that the doctors in Chili are not always understanding though, and therefore she preferred not to visit a gynecologist if not necessary. This feeling of not being taken seriously she relates to gender:

> ‘They (the gynecologists) are men you know, it’s like [if] I have a lot of pain ‘All women do’ - No, but it’s like a lot of pain ‘No, it’s normal, just the side effects’ - No, it’s not normal, like, you don’t feel it, you know. If you have cysts [they say] ‘it’s ok, it’s polycystic ovaries’, but they don’t pay a lot of attention [to] kind of, I think the symptoms feel…and there are not a lot of female gynecologists. There are.. maybe it’s easier to treat or try to explain your symptoms [to female gynecologists].’

Stephanie

Stephanie is a 26-years-old woman from New York, who got diagnosed with PCOS at age fifteen. She had a number of physical symptoms: Excessive bleeding during periods, unexplained weight loss, her hair was thinning out and she had acne on her back. However, the most impactful symptoms for Stephanie are related to the physical discomfort she experiences during her cycle. Before and during her periods, Stephanie has mood swings, nausea, cramps and headache. Especially the week before her period she describes as ‘terrible’. In particular, Stephanie describes that the fact that she does not know when her period is coming as causing a lot of discomfort, because it makes it hard to schedule activities:

> ‘I feel that I have no control over it, there is nothing I can do to change it. And you know, sometimes I am really motivated and I feel like ‘I wanna run five kilometers today’ and other times I’m just.. I feel horrible, and I don’t wanna move.. So, I never know what I’m gonna get. And I’m trying to keep track of my cycle, so I know when it’s gonna happen. Ok, maybe for this week, I’m gonna feel like crap. So I think that’s the best I can do, until they figure out a better way.’

Stephanie mentions stress as an important factor adding to her symptoms. She tells me that PCOS holds her back from getting more out of her life and challenging herself. She always has to think about the impact on her body and hormones whenever doing something that causes stress.

> ‘Yes, sometimes I think I would be really successful and really pushing myself if I didn’t have it, it’s kind of like discouraging me, you know, if I would do something wrong, something really bad can happen to my body and then I feel horrible and then it’s gonna be a start-all-over-again process...’

After the diagnosis, the doctors proposed that she would start with the birth control pill. Stephanie tried, but according to her, this did not provide any relieve. Stephanie tried out many different types of medications over the years, including metformin, herbal supplements, and she went ‘on and off birth control’. She also adjusted her food intake, trying out different types of diets: ‘I tried very healthy eating, now I’m like flexitarian, I sometimes eat fish, now I’m just trying out things myself..’

Stephanie feels that through these changes, she did bring about change: Her nails and hair got better, she gained energy, and she felt more emotional stable. Recently she took dairy out of her diet, and felt that her hair got much better as a result of this.

As she says about her lifestyle adjustments:

> ‘It definitely keeps me motivated, and gives me hope that there will be a change one day, that you go to the gynecologist and they won’t just jump down your throat with birth control pills and synthetic (?) hormones, I just don’t know why anyone would wanna impact themselves at any age to that. Meditation is definitely helping as well, and yoga, just try calming, I think when you have PCOS, you suffer from cortisol imbalances as well, so I definitely feel, the way I’m going about it now, helps me, but it’s taken almost eleven years, so…’

However, Stephanie also immediately relativizes the extent to which her lifestyle changes work: Although they can relieve the symptoms, they don’t cure the real cause of the disease, according to her.

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Laura and Stephanie both experience pain and physical discomfort, which they both describe as uncontrollable and all of a sudden. But they present the causes differently. Whether Laura ascribes it directly to the growth of cysts in her belly, according to Stephanie there is an underlying cause of hormonal imbalance that need to be addressed. Stephanie prefers to treat this naturally, and dislikes the chemical treatments proposed by doctors.

Laura perceives her agency in relation to the symptoms mainly as having the option to seek medical treatment. Stephanie is ambiguous about her agency. While on the one hand she says 'there is nothing she can do', on the other hand she mentions that her lifestyle adjustments do bring about improvement in her symptoms.

Preventing future health risks

The prevention of future health risks is one of the motives for some women with PCOS as well to engage in specific practices of self-care. As stated in the introduction, PCOS is associated with other health conditions such as diabetes, high blood pressure and cardiovascular disease (Goodarzi et al. 2012), which several of the women in this study were concerned about.

Eveline

Eveline is 45-years-old and the mother of four children. She got the diagnosis PCOS when she was 17 years old. At that time she had very irregular cycles. When she got the diagnosis, Eveline's conclusion was that she shouldn't wait for too long trying to become pregnant, because it might take long for her. She started by trying to conceive without any medical assistance, but that did not work. Then she tried to conceive with the help of Clomid, but again without any result, and experienced a lot of side effects. When another medication did not work either, Eveline and her partner decided to try in vitro fertilization. The very first time they tried, she got pregnant. After her pregnancies Eveline did not really experience symptoms of PCOS anymore. However, recently it was found that she developing different kind of health issues, which might be related to PCOS.

> 'I am watching my weight because I easily develop insulin resistance as was found during recent tests in the hospital. So I have to try to keep my weight below 60 kilograms. And therefore the doctors recommended me to go to the gym two hours a week to transform belly fat into muscles. Well, right now I manage to keep my weight in control. But in January I had a screening for cardiovascular disease, and it turned out that I had some arteriosclerosis. And since November I am having high blood pressure as well which I never had before, so right now I am starting to feel the negative consequences of PCOS, let's say it like that'.

Watching her weight Eveline does by jogging 10 kilometers a week, and making sure she does not eat too many calories. The reason she is watching her weight is definitely not because she is overweight; she even likes to weigh more than she does now. It is mainly to prevent insulin resistance. Doing so, she hopes this will prevent her from developing diabetes and arteriosclerosis.

> ‘Arteriosclerosis is not really something, something you want to have in this age and to this extent, but it is being monitored by the doctors. That gives me a sense of relief. I mean my father was 54 years old and he suddenly passed away and we don’t really know if that was the cause of his death, but genetic predisposition might play a role for me, in combination with the PCOS… So yeah, I rather have it discovered now and that I can do something about it.’

Other women mentioned as well that they were concerned about developing the health issues that were associated with PCOS, and that motivated them to adjust their lifestyle. Moreover, it was mentioned by a few women that the prevention of future health risks through diet is not only for their own benefit, but also for their future children’s. For example, as Joyce pointed out:

> ‘Yes, I think it is very important to take care of your health. And it is also like, once you have a child you have to quit your unhealthy lifestyle, because if I would pass away at age forty, then my child would be twenty, and maybe I would have another fifteen year old child or so, that is too young to lose your mom. So regarding the future, like right now I do not really have any health issues, I don’t have diabetes, I don’t have any heart problems and that kind of things, but that does not mean I won’t have that in the future.’

Therefore, Joyce sees it as a responsibility towards her future child that she loses weight.

Chapter 6: Online *cysterhood*

When searching for PCOS on google, numerous websites and blogs can be found, carrying names such as 'PCOS Diva', 'Healthy Hormones' or 'The Paleo Ballerina'. 'Cysters' is a commonly used term for women with PCOS on these pages, as well as on discussion fora. In this chapter, I will examine the role of the internet for women with PCOS in making sense of their condition and dealing with their symptoms. I distinguish between blogs and websites on PCOS, where information is shared from the writer to the reader and discussion groups, where women actively exchange experiences with each other.

In the first paragraph, I will explore the role of the internet as a source of information. For this aim, I will analyze the content of two popular blogs on PCOS - 'The Hormone Diva'[3] and 'PCOS Diet Support'[4]. In the second paragraph, I will describe the role of online communities of PCOS sufferers, and whether and how they play a role in participants' lives. For this aim, I give a brief overview of the content of the facebook group (PCOS Nederland – België[5]) where I placed my announcement for this study.

The internet as a source of information

The Hormone Diva

'The Hormone Diva' is run by 'holistic nutritionist and women's holistic health coach' Robyn, who has PCOS herself. The website's main slogan is 'Replace anxiety with joy to create happy hormones'. On the websites' homepage, articles are posted about food, exercise and emotional stability, with titles such as 'I was tired as a basket: Here's the seven foods I became obsessed with to fight fatigue'[6] and 'why cardio and boot camps are making you fat' [7]. The content of the articles follows a pattern. An article usually begins with addressing a certain problem, often from the perspective of 'Hormone Diva' Robyn herself. Take for example the article about the seven foods to fight fatigue. The article starts by describing Robyn's experiences in the past, in which she was struggling with extreme fatigue:

[3]http://thehormonediva.com/
[4]https://www.pcosdietsupport.com/blog/
[5]https://www.facebook.com/groups/829092073788650/
[6] http://thehormonediva.com/i-was-a-tired-basket-case-heres-the-7-foods-i-became-obsessed-with-to-fight-fatigue/
[7]http://thehormonediva.com/why-cardio-and-bootcamps-are-making-you-fat/

> 'Balling my eyes out, pounding my fists on the floor and heart palpitations. This was the embarrassing scene of just one of my breakdowns. It was another day of feeling like shit.'[8]

Robyn would try out many things, but nothing really works. She gets more and more desperate, feeling that there was nothing she can do about it:

> 'I felt like a prisoner in my body- just there to go along with whatever it decided to give to me. My doctor was no help either. While I was pleased she did do a little testing, when everything came back "normal" and all she could say was "some people are just tired", I felt like I was trapped for life'.[9]

But then, suddenly, there is the turning point: Robyn came to realize what was really the issue at stake.

> 'Not being one to take things lying down, I started doing some research. What were some causes of fatigue? Did any of them match the way I was feeling?'
>
> 'At first I didn't figure out exactly the physiological cause of my fatigue, I did stumble across several foods in my journey that improved my energy levels immensely. I became obsessed with eating these foods as often as possible. I even bought a couple of them in huge bulk online!'[10]

After the turning point, everything has become different:

> 'The change was like night and day. When I regularly used these foods, I wasn't so tired anymore. I could get through the day without a nap or a crash at 3PM. I could be around people without becoming snippy, irritable and just plain embarrassing myself with my moods.' [11]

The article usually ends with the concrete advice of Robyn of what helped her to get where she is now. Describing the problems from her own experiences, Robyn comes to symbolize the ordinary PCOS sufferer, who has a problem that many on the page can relate to and feel they lack control over. After the initial feeling of powerlessness, she heroically manages to 'fight' or 'overcome' the

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[8] http://thehormonediva.com/i-was-a-tired-basket-case-heres-the-7-foods-i-became-obsessed-with-to-fight-fatigue/.

[9] Ibid

[10] Ibid

[11] Ibid

issue through her own action. 'If I can do it, you can do it too!' seems to be the underlying message here.

The articles on the website do address a range of different topics, including fatigue, pain, overweight, or hair loss. In almost every article it is stated how important it is to 'balance the hormones' from the inside. Therefore, the 'hormonal imbalances' are seen as the main problem, caused by a set of lifestyle and environmental factors:

> 'Millions of women everywhere are suffering needlessly with hormonal imbalances. Busy, stressful lives, widespread toxicity, poor diet and sedentary lifestyle are contributing to these imbalances which seem to plague us.' [12]

Different types of hormonal imbalances are described, such as 'estrogen dominance' (a relative excess of estrogen in relation to progesterone) and insulin resistance. As the phrase 'happy hormones' already suggests, 'hormonal balance' is related to physical as well as emotional well-being on the page, and should be striven for in the treatment of PCOS symptoms.

This balance can be achieved through lifestyle, according to the page. As the article 'Crucial Strategies to Naturally Balance Your PCOS & Improve Your Emotional State'[13] lists 9 lifestyle adjustments:

1. High-fat, Low-Carb Breakfast
2. High Intensity Interval Training
3. Cinnamon
4. Yoga
5. Leafy Greens
6. Inotisol
7. Deep Breathing
8. Avoid Sugar and Dairy
9. B Vitamins

PCOS Diet Support

[12] http://thehormonediva.com/tag/hormones/
[13] http://thehormonediva.com/infographic-recently-diagnosed-with-pcos-9-crucial-strategies-to-naturally-balance-your-hormones-improve-your-emotional-state/

PCOS Diet support is another popular website devoted to PCOS. As the name already suggests, the website puts the emphasis on the role of diet in managing PCOS symptoms. A lot of emphasis is food on eating unprocessed foods, described as 'natural' or 'whole'. These kinds of foods are referred to as 'PCOS Friendly'[14].

This website is also owned by a PCOS sufferer: Tarryn, who describes herself as a 'PCOS Health Coach'. Tarryn used to struggle with all the 'classic symptoms' of PCOS including excess hair, acne and irregular cycles, and as she felt the available medical treatment did not address her symptoms, she started to look for information herself:

> 'Birth control or fertility treatment. Those were my options. Birth control didn't make sense if we were trying to start a family. A referral to a fertility clinic would take months and months to come through. Well, it wasn't good enough. I wasn't going to settle for that.
>
> So, I spent what feels like a lifetime doing my own research. Reading medical journal after medical journal, piecing together a plan. I was determined that I would not let PCOS tell my story. After my many hours of reading and research, I began making changes to the way that I eat. I cut out sugar, cut down on gluten and dairy and really focused on eating foods with a low Glycemic Load.'[15]

After telling her personal success story, Tarryn concludes by saying:

> 'And you can too. You are NOT alone in this journey. There is a whole community of women who know that struggle that you face today. Who are facing it alongside you. And more than anything, I want you to know that there is hope with PCOS. And that although PCOS may be a part of your story, it does not need to dictate the plot and story line. You can live the life that you want, without PCOS getting in your way'[16]

Also the impact of PCOS on the sense of femininity is being discussed on the page in different articles. In a blog called 'Kick PCOS in the Teeth and Celebrate the Woman within', Tarryn describes her own experiences as follows:

> 'Yesterday was a downer day I guess. I really feel that PCOS impacts on the core of who we are as women. Our bodies don't do what they were designed to do and we have little control over what is going on. The extra weight and unwanted hair growth makes us feel anything but feminine.

[14]see for example https://www.pcosdietsupport.com/recipes/pcos-friendly-coconut-honey-treats/
[15]https://www.pcosdietsupport.com/about-pcos-diet/.

[16] Ibid.

> But, it's time to fight back and celebrate the woman within! You know what I did at 3:30 yesterday afternoon? I started over and took some time for Tarryn. I had a long shower, straightened my hair, put some fresh clothes and make up on. It didn't completely resolve my blues but I felt so much better for it.'[17]

Saying this, Tarryn presents the sense of femininity as something that can be achieved by taking care of yourself. Furthermore, in the blog, some advices are provided – 'manage your insulin levels', 'avoid dairy', 'drink spearmint tea'- as well as tips for hair removal are provided.

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Both 'The Hormone Diva' and 'PCOS Diet Support' treat PCOS as much more than a problem in the ovaries. According to them, the underlying cause of PCOS is to be found in hormonal imbalances, brought about by lifestyle and environmental factors. At the same time, the solution is to be found in an adjustment of lifestyle, in which different factors should be taken into account: diet, avoiding chemicals, relaxation and exercise. By referring to 'hormones' as a coherent system that is responsible for both emotional and physical well-being, PCOS is approached holistically.

The blogs emphasize what women with PCOS can do in terms of daily lifestyle to balance their hormones, and, with slogans such as 'Kick PCOS in the teeth' , grant the woman a lot of agency to do so. To show that managing symptoms is really possible, 'success stories' are provided, often by the author of the blog.

The advice provided on pages such as 'The Hormone Diva' and 'PCOS Diet Support' cannot be seen as fully in contrast with dominant medical discourse on PCOS. The insulin resistance that is referred to on these pages as a cause of PCOS, is also part of the medical treatment for PCOS, as became clear in some of the stories in the previous chapter.

However, different from the dominant biomedical practice to advice lifestyle adjustments mainly to overweight PCOS women, both blogs suggest that diet could be a way to manage hormones for all PCOS women. Moreover, the blogs are less hesitant in ascribing all sorts of health issues to these imbalances, and present them as manageable. In addition to that, rather than viewing diet solely in terms of weight management and blood sugar, a lot of other factors should be taken into account according to these blogs: the hormonal effects of dairy, the use of chemicals in foods.

Therefore, in almost all pages that I encountered, the emphasis is placed on 'naturalness' of food and lifestyle. The birth control pill, which is often proposed as a form of treatment for PCOS women, is discouraged on many pages for the fact that it is not 'natural' and would rather create hormonal

[17] Ibid.

imbalances than solve them[18]. In this sense, the discourse of these self-care pages contradicts official biomedical discourse on the treatment options for PCOS. The tendencies I described above – the holistic view on PCOS, the strong focus on individual agency and the contrast between natural and chemical treatments – are very regular patterns in self-care blogs about PCOS.

Having a look at the different blogs on PCOS, blogs do not agree on what is the best diet for PCOS. Dietary advices vary from eating vegan (see for example 'vega-licious'[19]) to the paleo diet (see for example 'The Paleo Ballerina'[20]), which includes a lot of meat and fish instead. To put it shortly: The blogs agree that health is in your own hands, however, they do not fully agree about how to manage it.

The Facebook group 'PCOS Nederland-België'

The Dutch-Flemish facebook group PCOS Nederland-België ('PCOS Netherlands – Belgium) has 1120 members. On average, five messages are posted every 24 hours. Below, I will discuss four different types of posts that are posted in these groups: posts in which health advice is provided or asked for, posts for confirmation, post for emotional support and motivational posts.

First of all, in a large number of posts, a member is asking the others for advice. Her physician recommended a certain treatment, and she wants to hear the experiences of others. She is struggling with immense hair fall, and is asking other members in the group for tips on shampoos. Or, she wonders what the best ovulation test is. Sometimes, a woman asks advice about how to deal with particular aspects of PCOS, such as: 'How do you tell or family about PCOS?'. Many other women would share their experiences. Another type of posts, are the ones in which a woman is struggling with a particular health-related problem, and wants to hear other's thoughts about it. Is it normal? Is it PCOS related? And should she see a doctor? These kinds of posts are about pain issues, other physical symptoms, skin or hair issues. When the post is about hair or skin issues, it often includes pictures. A woman would for example share a picture of the hair she has lost during her shower and asks whether it is normal and if others lose the same amount of hair. Other women would respond by saying that they lose the same amount or even more, sending her support or give her advice about what to do against it.

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[18] see for example http://thehormonediva.com/exciting-natural-alternatives-to-hormonal-birth-control/.
[19] http://www.vega-licious.com/healing-pcos-with-plant-based-diet/
[20] http://www.thepaleoballerina.com/about/

Another very common type of posts, are the ones in which a woman thinks she is pregnant, but asks others for confirmation. She shares a picture her pregnancy test. What do the others think, do they see that faint, second line as well? Or is it just imagination? Responses to these posts are either 'congratulations, you're pregnant!' or 'sorry girl, I don't see it'.

Another type of posts, are the ones in which a woman just needs to vent. She has been trying to get pregnant for so long, but got her period again. She feels ugly. Or she does not manage to lose any weight. She does not ask for specific advice, but just wants to share her experience and get some support from others.

Finally, there are the posts through which the author wants to give the others motivation by sharing her story. She tells about how much weight she has lost – and often includes 'before and after' pictures in her posts – and encourages others not to give up trying. A very special type of these motivational posts, are the ones in which a woman announces that she finally got pregnant.

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Although participants were ambiguous about how they valued self-care blogs, facebook groups and online fora were evaluated very positively. As Babette, one of the participants, tells about what she gets out of this facebook group:

> 'Well, advices about how they deal with daily life, how they deal with treatments… Yes, that it also, that fortunately I am not the only one who has frustrations once in a while and yeah, that you also read that they want to share it and…that you're not alone, that you're not the only one. I really appreciate to read that of others, but also to share things with each other. That you can ask questions to each other, or that you can be completely broken down. People who understand you.'

Discussion and conclusion

In this thesis, I have described the self-care practices of women with polycystic ovary syndrome. As the many stories in this thesis made clear, polycystic ovary syndrome is a diverse condition that affects women in many different ways. Through the stories of women living with this condition, I illustrated how self-care is practiced to manage, cure or prevent the different symptoms of polycystic ovary syndrome, such as excessive hair growth, acne, overweight and infertility.

In chapter four, I described the experiences of getting diagnosed with PCOS. By presenting the stories of three women, I provided insight into how the diagnosis of PCOS can impact one's perception on health and risk, and can result in different types of help- and information seeking behavior.

In chapter five, I gave an overview of the ways in which self-care is practiced, varying from dietary adjustments, to skin care, to talking about one's feelings with others to improve emotional well-being. The chapter illustrates that self-care practices in women with polycystic ovary syndrome are motivated in many ways, such as a wish to maintain or restore a sense of femininity, to improve fertility, to lose weight, to relieve pain or to prevent long-time health risks. The motivations that underlie self-care practices cannot be perceived as isolated, but work upon each other in complex ways. For example, it is through pain relief that emotional well-being is established, and it is through hormonal balance that fertility is promoted. Moreover, many forms of self-care, particularly the adherence to certain lifestyle regimens, affects the body in more than one way. For example, losing weight through a specific diet is thought to promote fertility, but also serves to prevent long-time health risks. Similarly, by balancing one's hormones through diet, the skin is thought to improve and even unwanted hair-growth can decrease. Self-care in relation to PCOS, therefore, is a holistic process. However, it is also a very uncertain process, in which women feel uncertain about how and to what extent some of these practices actually have an impact on their bodies.

The participants also indicated that material concerns play a role in their choice of self-care practices. As self-care is something they often have to pay for themselves, they constantly have to balance between costs and benefits and have to make conscious choices about whether a certain form of self-care is worth the investment - in terms of money as well as time- and has enough chance of benefiting them.

Because a lot of information on self-care for PCOS is provided on the internet, in chapter 6 I explored the role of online communities. I found that online information is experienced as a useful source for participants to learn about possible explanations for PCOS and about self-care practices. Some participants adhere to lifestyle regimens they learned about through the internet and perceive

this as a benefit for their well-being. However, the online health-related information is also experienced as confusing by many participants. Some indicate that they struggle to find the information relevant for them and to judge whether information is accurate. Moreover, in relation to stories of fellow sufferers, participants point out that the effect of internet information is heavily dependent on the nature of stories they encounter: whether ‘success stories’ of others can provide motivation, ‘horror stories’ about infertility or excess facial hair can do exactly the opposite, leaving them with the feeling that they are not in control. Online contact with fellow sufferers through discussion groups and internet fora are generally experienced as valuable though, by providing women advice, emotional support and motivation. Several participants indicated that they feel they would benefit from real-life encounters with fellow sufferers, and that online contact could be a tool to establish this.

I addressed the self-care practices of women with PCOS in the context of theoretical debates about normative femininity and beauty, self-care and agency, risk and the de-professionalization of medicine. Below I will discuss how this study relates to these concepts and what it can tell about the workings of these large concepts in the context of dealing with a chronic health condition. In line with earlier studies, I found that many of the women feel that polycystic ovary syndrome negatively affects their sense of femininity. Therefore, the practices they engage in are often aimed at restoring femininity by removing body and facial hair, or indirectly by following a certain lifestyle regimen that is thought to relieve the masculinizing symptoms of PCOS. The experience of women with polycystic ovary syndrome indicates that health and beauty are strongly intertwined in this context: Excess body and facial hair are addressed as symptoms of the disease, and therefore promoting health and restoring femininity go hand in hand. In a somewhat similar way, in their accounts the women relate to infertility and loss of menstrual cycle as both health concerns as well as disruptions of femininity. Although the women I have spoken to wish to, many of them struggle to perform normative femininity successfully, which is a result of their symptoms. Coping mechanisms to deal with feelings of being less feminine can take a number of forms. It includes active attempts to treat and manage PCOS symptoms (e.g. through shaving), to hide symptoms, to compensate for their symptoms by actively performing femininity in different ways, or to shift their understandings of femininity in ways that it does not necessarily have to include a smooth skin or fertility. Because of its symptoms and the limited ability to control them, polycystic ovary syndrome disrupts the idea of normative femininity as a natural state. This is not in the last place true for the women who suffer from PCOS themselves, who indicate to be very conscious about the gendered features of their body and behavior, and how this comes across to others.

In the process of practicing self-care, women with polycystic ovary syndrome are ‘active, choosing, empowered agents’ (Mitchell 2010: 112) deciding about their own health and how this should be improved. The individual search for causes of polycystic ovary syndrome and the search for solutions in terms of individual lifestyle choices reflects a ‘healthist’ (Crawford 1980) perspective on health, in which participants render themselves responsible for their health. As described in the literature, 'healthism' includes the idea that people are both responsible for managing their own health, as well as capable of doing so. However, my research indicates that participants are highly ambiguous towards their capability to influence their own health, although they play an active role in searching health information and making conscious choices about self-care practices. The practices they engage in are surrounded by uncertainty about its effects, and quit or change practices regularly as a result. This illustrates that although individuals are increasingly rendered responsible for their own health and make conscious choices in relation to health, ‘healthism’ does not necessarily imply that people perceive themselves as fully capable of managing their health, and their perception of agency in relation to health is ambiguous.

In the theoretical framework I placed the self-care practices of PCOS women in the context of a ‘risk society’ (Beck 1992) in which people have to navigate through often contradictory discourses on health. This risk society goes hand in hand with the loss of authority of institutions such as the medical world, and a ‘de-professionalization’ of medicine, which the internet helps to facilitate (Hardey 1999). Different authors (Hardey 1999, Kivits 2009) emphasize the agency of individuals in selecting and ignoring health-related information online. Although this process can be seen as an execution of agency, paradoxically, online searches can also limit the sense of agency of an individual in influencing health, when reading about the negative stories of fellow sufferers, or being unable to find accurate information. As stated above, sometimes participants indicated that they feel they lack the expertise to judge about what is accurate, and therefore prefer to consult a physician. This illustrates that ‘de-professionalization’ of medicine does not have to imply that alternative discourses on health are seen as just as valid as dominant medical discourse. Instead, in some cases, it is the physician who is expected to provide certainty in the sea of uncertainty.

One of my motivations to conduct this research was to assess how practices of self-care relate to prescribed medical treatment. In this research, self-care takes place instead of, in addition to or even in collaboration with medical treatment. Sometimes self-care is recommended by doctors and other health professionals, such as nurses of nutritionists. This is for example the case for participants who follow certain skin care regimens based on advice from a dermatologist or follow a diet prescribed by a nutritionist. Self-care, then is part of the treatment regimen the patient receives, and the patient is actively monitored in this process. In general, I found that the women who

engaged in prescribed forms of self-care were more confident about the working of these forms of care.

Self-care also takes place outside of the medical domain. There are several reasons for this. Participants indicated that existing medical treatments often fall short in addressing their needs. I heard from many participants that the only treatment that was offered to them was the birth control pill, or in the case of a wish to conceive, fertility treatment. However, the women might have other concerns at that moment that she feels are just as important, such as excess body or facial hair. She then feels these symptoms are not addressed properly. Another reason why some women engage in forms of self-care outside of the medical domain, is because they feel their symptoms are not rightfully understood by the physician. The physician, for example, might think that insulin resistance does not play a role in the situation of a PCOS woman because she is lean, but she might see this differently. As a result, she will explore this 'underlying cause' herself, often with the use of online sources.

This study has a number of strengths and limitations. An important strength is the fact that this research provides in-depth information about the relationship between the illness experience, self-care practices, information seeking and care needs, which is provided by the method of qualitative interviewing. In contrast to survey research, this created space to elaborate on certain self-care practices and to discuss forms of self-care that were not anticipated. However, a strong limitation of the study is its small sample size, which makes it unclear whether findings can be generalized to a larger population of PCOS sufferers. As PCOS affects women in different ways, a small sample size is susceptible to bias. Additional research amongst a larger population should be conducted to assess the wishes and needs in relation to care for women with polycystic ovary syndrome.

Based on the study, I would like to make a few recommendations. First of all, I recommend health-care professionals working with PCOS-women to assess the different needs or concerns a woman with polycystic ovary syndrome has. Whereas existing medical treatment options for PCOS are mainly aimed at restoring the menstrual cycle through the birth control pill or assistance with getting pregnant (Dutch Society for Obstetrics and Gynecology 2005), this research once again made clear that 'PCOS is not only a fertility problem', as one of the participants said. It can affect women physically, emotionally and socially, and by assessing how PCOS impacts the woman's life, the physician can refer her to other specialists including nutritionists, skin therapists, psychologists or hair laser removal therapy. More research is necessary on the effectiveness of different types of treatments in PCOS women (Setji et al. 2014), but being aware of the existing treatment options that

are available, the physician can inform the woman about options and their insurance coverage, and refer her according to her needs.

Secondly, I would propose to create a Dutch website that is specifically devoted to addressing the concerns of women with polycystic ovary syndrome. Such a website can provide information on many different aspects of living with PCOS, where different kind of specialists can contribute to, including gynecologists, nutritionists, psychologists and beauty therapists. In addition to providing information, it can be a space to share experiences and also serve to facilitate real-life encounters between women with polycystic ovary syndrome.

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Appendix 1: Interview guide

0. Can you shortly introduce yourself?
1. When have you been diagnosed with PCOS and how did that go?
2. Which symptoms do you experience?
3. How do these symptoms affect your daily life? Can you give me some examples? How do you feel about this?
4. How do you deal with the symptoms you experience?
5. At which moments do you feel most affected by PCOS?
6. Do you receive any form of regular medical treatment, or have you done so in the past? How do you experience this/have you experienced this?
7. Do you receive any form of alternative treatment, or have you done so in the past? How do you experience this/have you experienced this?
8. Are you making any adjustments in terms of lifestyle (e.g. diet) which are related to PCOS?
9. Where did you get your information from, related to these changes in lifestyle?
10. Do you notice any changes in how you feel which you ascribe to these changes in lifestyle?
11. Have there been any changes in your daily care routine since you struggle with these symptoms?
12. Which aspects of your body do you value?
13. Which aspects of your body do you value less?
14. What aspects of your body would you like to change? Why?
15. Who in your environment did you tell about your PCOS? How do you discuss this topic?
16. Are you in contact with fellow sufferers? Through which chemmals, and what do you get out of this contact?
17. Is there anything you would like to add?

Appendix 2: Self-care questionnaire (Dutch)

Instructies:

1. Vul het over dagelijkse verzorging en levenstijl in tijdens twee dagen, waarvan één weekdagen en één weekenddag (bijv. maandag, woensdag en zaterdag). Deze dagen hoeven niet persé in dezelfde week te vallen.
2. Bij ‘uiterlijke zorg’ gaat het om alle handelingen die met uiterlijke zorg te maken hebben, al dan niet gerelateerd aan PCOS. Denk hierbij aan make-up gebruik, tandenpoetsen, scheren, wenkbrauwen epileren, aanbrengen van gezichtscréme et cetera.
3. Bij ‘medicijn- en supplementgebruik’ gaat het om het gebruik van (reguliere of alternatieve medicijnen) en aanvullende supplementen, zoals vitamines of kruidensupplementen.
4. Bij ‘voeding’ gaat het om wat je op die dag hebt gegeten.

	Dag 1 (weekdag)	**Tijd**	**Dag 2 (weekenddag)**	**Tijd**
Uiterlijke zorg				
Medicijn- en supplement gebruik				
Voeding				

Appendix 3: List of self-care blogs and web pages included in analysis

1. https://healthyhormones.eu/
2. http://www.mesaverdeblog.nl/van-pcos-afgekomen/
3. http://www.pcos-solutions.nl/blog/
4. https://opwegnaareenkind.wordpress.com/
5. https://nl.pinterest.com/pcosdiva/
6. http://het-traject-met-pcos.blogspot.nl/
7. https://www.pcosdietsupport.com/
8. http://www.pcosnutrition.com/articles-blog/
9. http://www.ginelletesta.com/blog/living-with-pcos-polycystic-ovary-syndrome
10. http://www.ladiesbalance.com/directory-of-pcos-blog-bloggers-and-forums/
11. https://www.pcos.com/blog/
12. https://blog.yourtea.com/pcos-east-vs-west/
13. http://lifeabundant-blog.com/
14. http://themasseyspot.blogspot.nl/p/pcos-to-pregnancy.html#.WQMVX9LyjIU
15. https://www.girlsgonestrong.com/blog/hormones/pcos-nutrition/
16. http://www.pcosaa.org/pcosa-awareness-association/
17. http://amyplano.com/blog/
18. https://symptopro.org/blog/entry/self-care-tips-for-pcos.html
19. http://www.ovarian-cysts-pcos.com/pcos-blog.html
20. https://www.mypcoskitchen.com/category/blog/
21. http://conqueryourpcosnaturally.com/blog/
22. http://thecurvyblogger.com/post/932281706/pcos-all-you-need-to-know
23. http://www.pcosdiet.typepad.com/
24. http://www.thepaleoballerina.com/about/
25. http://positivepcos.com/pcosandskin.html