

‘This Feeling of Multidimensional Disease’: How Women with PCOS Narrate Their Experience with Self-Tracking Apps and Social Media¹

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Abstract: Polycystic ovary syndrome, or PCOS, is a common condition that combines such symptoms as absent or irregular menstruation, elevated levels of ‘male’ hormones, excess facial and body hair, and problems with glucose metabolism. Receiving a PCOS diagnosis can be a disorienting experience. This article focuses on this medical condition to explore the role of different digital technologies in managing women’s health across public and private domains. Relying on seventeen semi-structured interviews with Danish women, I suggest that self-tracking mobile applications and social media provide PCOS patients with different modes of caring and drawing boundaries between public and private. Whereas applications are designed according to the capitalist logic of paying to manage your health and fitness, social media offer solidarity and mutual care. This article elucidates how patients use self-tracking apps and social media to make sense of their unique configurations of symptoms, often without any connection to their clinical visits and communication with medical providers. I employ Annemarie Mol’s theory of the logic of choice vs the logic of care and the notion of ‘social-material networks of biosensing’ by Mette Kragh-Furbo et. al. to argue that social media partially compensate for the inadequacy of self-tracking apps for handling PCOS and offer care and solidarity through the sharing of personal stories.

Keywords: polycystic ovary syndrome, self-tracking apps, social media, the logic of choice, the logic of care, social-material networks

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'I think it gave me a bit of calm, knowing all these stories and knowing that it does not look only one way.'² This is how Paula,³ a Danish woman in her early twenties, evaluated her experience with social media discussions of a medical condition that she has: polycystic ovary syndrome (PCOS). PCOS is relatively common: it affects 5% to 20% of women and AFAB⁴ persons worldwide (Hachey et al. 2020). In medical terminology, PCOS is not a 'disease' but a combination of several symptoms, such as absent or irregular ovulation and menstruation, elevated levels of 'male' hormones, excess facial and body hair, and problems with glucose metabolism (Mousa, Tay, Teede 2023). Receiving a PCOS diagnosis can be a disorienting and even scary experience: this is what I learned from my interviews with Paula and sixteen other women. The quote from Paula suggests that social media provides information about the diversity of PCOS experiences and a connection to fellow sufferers, and this information and connectedness can mitigate the frustration of falling outside the medical and social norms of health, fitness, and femininity. The idea that technologies can not only diminish but also reinforce women's agency echoes research in feminist HCI (human-computer interaction) on the role of digital technologies in the everyday bodily experience – health and illness, menstruation and pregnancy, and ageing and menopause (Bardzell 2010; Bardzell et al. 2019; Epstein et al. 2017; Homewood 2018; Lazar et al. 2019; Taylor, McDonagh, Hansen 2017). Social media platforms like Facebook and Instagram (Gammelby 2021; Tiidenberg, Baym 2017; Warfield, Abidin, and Cambre 2020), platforms for telecommunication between doctors and patients (Mort, Finch, May 2009; Nicolini 2007; Oudshoorn 2011; Pols 2012), and self-tracking apps (Epstein et al. 2017; Esmonde 2020; Fellows, Smith 2022; Lazar et al. 2019; Lupton 2013; Sanders 2017a; Smith, Vonthethoff 2017) have been analysed as re-framing the visions of health and wellbeing and redrawing the boundaries between private and public.

How do digital technologies impact intimate lives in the context of PCOS, a common but little-discussed condition that challenges both medical and social gender norms? Furthermore, does the connectedness that digital technologies offer PCOS patients come at the price of losing privacy? I suggest that self-tracking mobile applications, including those categorised as FemTech, technologies targeting women's health (Balfour 2023), on the one hand, and social media, on the other hand, provide PCOS patients with different modes of connecting and drawing boundaries between public and private. I will investigate these different modes based on ethnographic

² The quotes in this article are cited verbatim as spoken by interviewees whose first language is not English, and their grammar and word choice have been edited.

³ All names used in this paper are pseudonyms.

⁴ Assigned female at birth.

fieldwork. I will elucidate how patients use self-tracking apps and social media to make sense of their unique configurations of symptoms, often without any connection to their clinical visits or communication with medical providers.

The article starts by outlining the transition of a PCOS diagnosis from a clinical to a domestic setting and the role of digital technologies, namely self-tracking mobile applications and social media. The domestic handling of PCOS can be considered a part of 'e-escaped medicine' – medical knowledge that has moved from medical institutions to cyberspace (Nettleton 2004). Next, I will zoom in on the use of self-tracking mobile applications in PCOS and explain it through the notion of 'the logic of choice' (Mol 2008) – the vision of individuals as autonomous and able to maintain their health and fitness by purchasing and using specific services. Siding with recent criticisms of self-tracking and 'mobile health', I will demonstrate how the material realities of PCOS challenge the capitalist logic of choice and produce 'mundane' data (Pink et al. 2017). Next, the article moves to online support groups and influencers' accounts on social media that allow the 'sense-making' (Kragh-Furbo et al. 2018) of PCOS. I will suggest that such groups help mitigate against the disappointment from self-tracking apps by being more sensitive to the diverse sets of symptoms and needs of women with PCOS. Further, I will introduce 'the logic of care' to analyse online communities as sites that enable the sharing of individual patient experiences. Women with diverse PCOS symptoms look for relatable stories in online communities and thereby participate in caring for each other without offering any 'perfect' solutions. They navigate between the wish for privacy and the search for connection and recognition. In conclusion, I will argue that 'social-material networks of biosensing' (Kragh-Furbo et al. 2018: 48) offer an alternative to the capitalist vision of an empowered woman who can afford to manage her health and blur the boundary between private and public domains.

Data and method

Between January and December 2023, in Denmark, I conducted 17 one-to-one semi-structured interviews with Danish women aged 23 to 42 (see Table 1). I recruited the interviewees (whom I will call 'respondents') from Danish-language social media communities: a private support group on Facebook and a private forum managed by an Instagram influencer. This influencer later also posted information about my research openly in her feed, which attracted a few more respondents. Sixteen interviews took place face-to-face, in a respondent's home or a café, and one interview was conducted via a video call.

All the interviews were conducted in English because the level of my spoken Danish is not yet good enough for this purpose. Occasionally, my respondents used Danish

terms when they did not know the English equivalents, and later I translated these. The quotes are slightly adjusted to avoid repetition while the idiosyncrasies of the spoken language and the specificity of speaking in a foreign language are preserved. If a respondent emphasised a certain word verbally, I highlight it in italics.

The interviews lasted between forty minutes and two hours, depending on how much a respondent wanted to tell. In addition to recording the oral interviews, I provided a drawing pad and crayons so that the respondent could use drawing to visualise her story. Only two respondents used this option. The fieldwork was approved by the Data Protection Officer. All the participants signed a consent form before the interviews.

I used two criteria for selecting respondents: having a PCOS diagnosis and experience with the Danish healthcare system concerning this diagnosis. Even though PCOS is often related to subfertility, reproductive health was not at the centre of my research. Therefore, my interview pool included women in various situations regarding reproduction: those who were going or had gone through fertility treatment; those who became pregnant easily (but had other PCOS-related health issues); those who were not yet thinking about children; and childfree women. That is, fertility status was not a selection criterion.

The fieldwork's demographic was limited to cisgender middle-class women, only two of whom were women of colour. In this article, I use the term 'women' to refer to my respondents, while keeping in mind that PCOS can affect people assigned female at birth who have different gender identities.

Sixteen of my participants currently reside in Denmark; of these sixteen, two moved to Denmark as adults, and one was adopted by a Danish family from abroad and brought to the country as an infant. One participant experienced her first PCOS symptoms in Denmark but received her diagnosis after moving to Norway. I felt the inclusion of this respondent in the pool was justified because the healthcare systems in Nordic countries are very similar, and this respondent regularly visits and spends time in Denmark. I assigned a pseudonym to each respondent and removed any precise geographic details. I transcribed all the interviews verbatim and performed a thematic analysis of the transcripts and accompanying drawings, combining theoretical and inductive (data-driven) approaches (Braun, Clarke 2006).

Unlike the researchers who scrutinised patients' online discussions (Kragh-Furbo et al. 2018), I rely on my interviewees' accounts of their use of social media. This information, though indirect, reveals each patient's own perspective on the role of social media in their everyday handling of PCOS and making sense of the data from their self-tracking applications.

Bringing PCOS home

As a chronic condition, PCOS is experienced in a domestic space daily. After the doctor announces the diagnosis in a clinic, the patient goes home with the burden of processing this information and figuring out how to live with this syndrome, about which she had previously known little. How does she handle this challenge? In the last two decades, digital technologies have helped patients with chronic illnesses (Oudshoorn 2011; Pols 2012; Wada, Wallace 2022). PCOS, too, is a chronic condition. Its management has been affected by digital technologies that are available at home and at one's fingertips. Moreover, PCOS is a gendered condition: it challenges the medical and social norms of femininity and fertility. Some of the technologies used by people with PCOS are dedicated to tracking menstruation and ovulation, which are still mainly associated with womanhood and femininity despite the growing discussion of a more gender-inclusive approach to these biological functions (Epstein et al. 2017). Other technologies aim to gather less explicitly gendered data on, for instance, sleep, exercise, nutrition, and blood sugar levels. Nonetheless, these parameters are still gendered: thinness and fitness are values imposed on women by marketing and advertising (Sanders 2017; Al Derham 2023). My fieldwork revealed the details of using digital technologies in daily life with PCOS.

According to my interview data, gynaecologists provide only a minimum of information about PCOS when informing their patients of this diagnosis. Typically, they advise the patients to 'eat healthy and exercise' and ask them to return when they plan to have children. That is, women with PCOS are encouraged to modify their lifestyle for optimal health and fertility outcomes. This medical advice is in tune with the capitalist logic of self-improvement (Ward 2015). Doctors, however, rarely go beyond generic advice and explain what exactly 'eat healthy and exercise' means in the case of PCOS. At best, they hand patients a folder or booklet with basic guidelines on lifestyle and the pharmaceutical management of symptoms. This, for example, happened to Cecilie, Veronica, and Sofia: none of them received more detailed guidance from their gynaecologists. Several respondents said they felt confused and neglected by their doctors and nurses when they left the consultation room. Some complained about the insufficiency of knowledge about PCOS on the part of Danish gynaecologists as well as GPs. Veronica, for example, wondered, 'We are told that we need to eat vegetables and fruit and all that stuff, right? So, what's happening in the body and why? And also, why are the hormones so different [for different women with PCOS]?' She could not find sufficiently distinct and personalised advice for women with PCOS with different body types and different hormonal profiles. This made her question the informative value of the diagnosis itself: 'Why do you put one label on something that looks so different?'

To make up for the lack of attention and information received from their health-care provider, patients turn to digital technologies when they get home. They google PCOS and its specific symptoms. They learn to critically assess the sources they find – or, like Cecilie, a trained journalist, they utilise their professional skills to evaluate the credibility of information found on the Internet. Some of my respondents were satisfied with the facts and guidelines provided by the official websites of the Danish Health Authority Sundhed.dk and Netdoktor.dk, and the websites of the British NHS and the American Mayo Clinic. Ane Kathrine Gammelby points out the functional continuity between such websites and the family health encyclopaedias that used to be found in some homes in the 20th century (Gammelby 2021: 11). The medical research database PubMed similarly offers information based on clinical trials and systematic reviews, but its use requires extra effort to assess the quality of the research papers collected there. Rikke, an interviewee who was always keen to learn about the connection between PCOS and other physical and mental conditions, told me that she visited PubMed regularly. Furthermore, nearly all my interviewees mentioned browsing through the social media accounts of medical professionals providing information about PCOS and of influencers with this condition, who are sometimes called ‘expert patients’ in the medical humanities literature (Cordier 2014; Fox, Ward, O’Rourke 2005).

Collecting online sources is usually the first step in engaging with PCOS digitally. The next step is tracking PCOS through various mobile apps and following online communities. These two modes of digital lives with PCOS – self-tracking and communicating online – are at the centre of this article. They correspond to the global process of ‘repositioning healthcare, locating it within the domestic domain rather than the clinic’, and, at the same time, the transition from the physical to the virtual so that ‘the home becomes one node of a dispersed network of healthcare technologies’ (Lupton 2013: 261). Sarah Nettleton came up with the term ‘e-scaped medicine’ to describe the transition of medical knowledge from the clinic and the laboratory to various locations, including the home, through information technologies. The home thus becomes a part of ‘cyberspace’, where ‘knowledges of the biophysical body’ move out of medical institutions (Nettleton 2004: 673).

For my interviewees, e-scaped medicine is not about communication with doctors. Once they received a PCOS diagnosis, they were rarely offered follow-up visits to their healthcare provider, whether virtual or in-person. However, self-tracking apps and social media frequently appeared in their stories. Below, I will discuss how the logic of self-tracking relates to the needs of PCOS patients, after which I will suggest that social media can mitigate the shortcomings of the apps.

Self-tracker apps: the logic of choice

Self-tracking apps can be categorised as part of ‘m-health’ (where ‘m’ stands for ‘mobile’) or FemTech (Balfour 2023b; Lupton 2012). Women and people who menstruate use a variety of apps – from fitness and calorie trackers (Didžiokaitė, Saukko, Greiffenhagen 2018; Esmonde 2020) to menstruation and fertility trackers (Balfour 2023; Epstein et al. 2017; Homewood 2018; Polzer et al. 2022; Kragh-Furbo et al. 2018). Studies in feminist STS (science and technology studies) and HCI (human-computer interaction) have critically assessed such trackers as playing an ambivalent role: they empower women by giving them greater awareness of their bodies, while at the same time they reinforce cis- and heteronormative stereotypes and further self-surveillance. Jessica Polzer and her colleagues, writing specifically about menstruation and fertility tracker apps (MFTAs), call the latter role ‘biopedagogical’: the apps’ designers present the body as a mystery to be solved. Furthermore, ‘bodily demystification promised by apps, and suggested in many of the testimonials, is ultimately achieved through the users’ participation in vigilant self-surveillance’ (Polzer et al. 2022: 170). Mikki Kressbach focuses on a different potentially negative effect of MFTAs: while they seemingly inspire users to break menstrual taboos, through their neutral icons and their logic of predicting menstrual cycles ‘they reinforce the perception that menstruation is an entirely private experience of self-management’. Offering users greater knowledge of their bodies, MFTAs allow planning activities around menstrual cycles so that they remain hidden: ‘The logs function as a way to monitor physical and emotional changes, and by detecting patterns, they may allow users to better conceal traces of their menstrual status’ (Kressbach 2021: 248). Therefore, the protection of users’ privacy comes at the price of reinforcing menstrual taboos and bodily shame.

I suggest that the biopedagogical messages of MFTAs operate according to what Annemarie Mol explains is ‘the logic of choice’, based on the neoliberal idea that the individual is responsible for their health and not dependent on public welfare services (see also Ward 2015 for the connection between neoliberal economic policies and the notion of self-care). The marketing of medical devices such as blood glucose monitors tells prospective consumers that ‘choice is a good because it offers individual autonomy’ and that everyone is entitled to make normative judgements about the best possible treatment (Mol 2008: 85–86). As Polzer and her colleagues demonstrate, the choice to use an MFTA is the choice to meticulously share personal information. This leads to learning more about one’s own body based on the app’s predictions. Its users become ‘prosumers’: they actively provide data about their mental and physical condition for the app’s algorithm so that they can consume the customised statistics on and predictions for their menstrual cycles (Polzer et al. 2022: 172). This does not apply only to MFTAs. In her book on self-tracking technologies

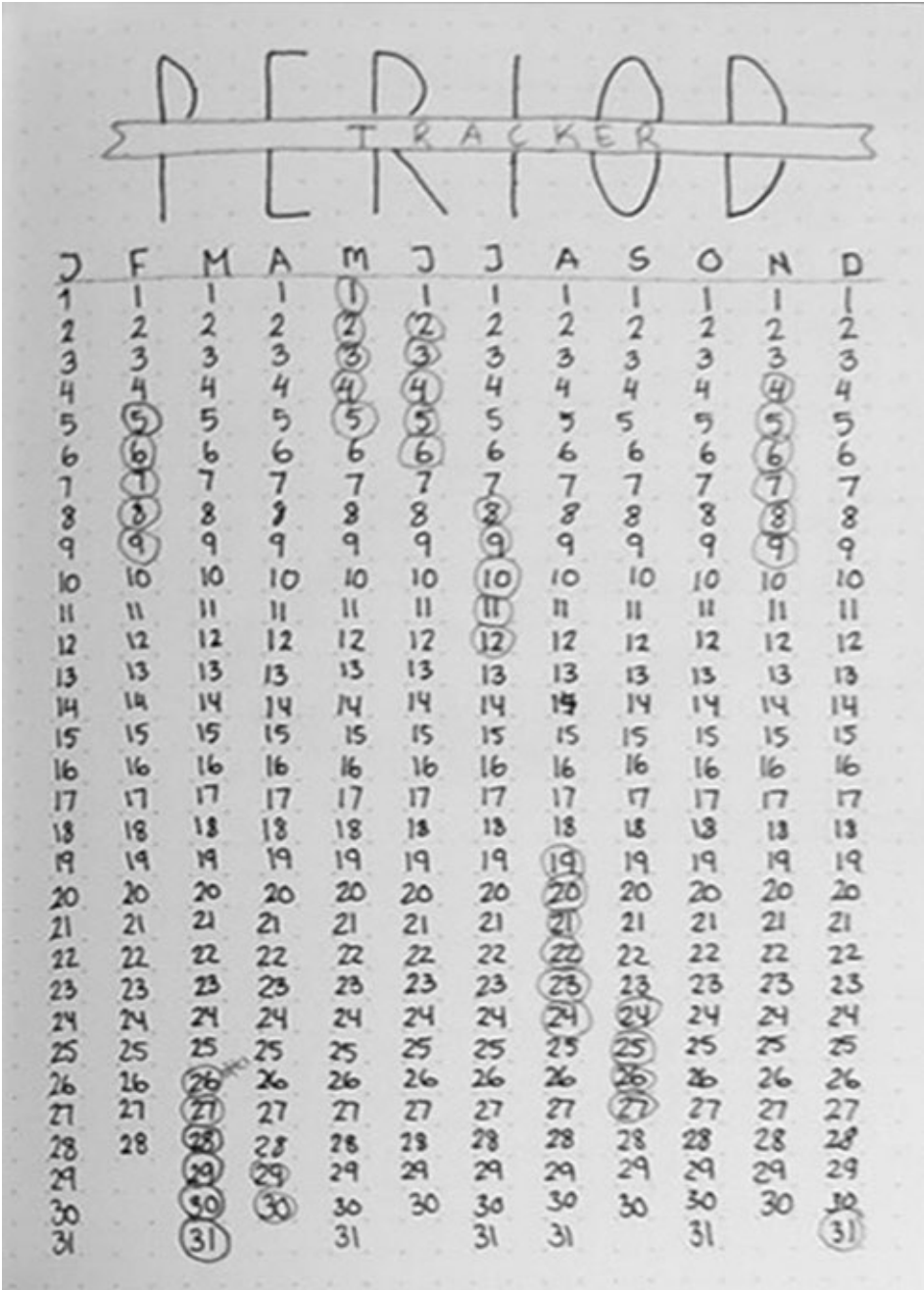
in general, Lupton describes users who choose which ‘lively data’ (meaning data that reflect both bodily functions and social relationships) to collect and how to collect it (Lupton 2016). While one may refrain from sharing certain data with the app (Esmonde 2020), the logic of choice presupposes active patient engagement in self-monitoring to obtain maximally precise customised information (Lupton 2013). Therefore, keeping certain symptoms or behaviours (such as eating or exercising) private and invisible to the apps would compromise the goal manifested by the market of health technologies: becoming knowledgeable about one’s body and capable of achieving excellent health and fitness.

However, as Mol notes, the logic of choice does not fit well with a life with chronic medical conditions: ‘When it comes to the question as to which treatment, product, goal or life is best, the logic of choice provides no answer.’ (Mol 2008: 85) As my interviews show, the choice to share as much data as possible does not guarantee accurate predictions or explanations of menstruation patterns. One common PCOS symptom is irregular or absent ovulation and menstruation. Some of my respondents barely have a period once a year and do not see any point in tracking their cycle. Others have fairly regular periods and can therefore track them just like women without PCOS do.

Those who have a few irregular and unpredictable periods now and then are in the trickiest situation. For example, Esther was quickly disappointed with the popular app Clue because her periods happened only occasionally and did not fit the app’s algorithm. When she entered her physical symptoms into the app, Clue could, for example, ‘predict’ that a period would start in 10 days, and then 20 days would go by without any sign of it. That is, the ‘biopedagogical messages’ of the app proved powerless in the face of the physical reality of PCOS (Lupton 2016). In addition, Esther did not see the point of tracking her emotions, an option that Clue offers, because she could never be sure that a particular mental state had anything to do with her long and irregular menstrual cycles: ‘I don’t rely on apps to tell me how I feel on a certain day because if it were memorable, I would remember it.’ She quickly abandoned Clue and started using a bullet journal instead to track both her emotions and her period (Figure 1). In this case, the low-tech, material solution proved to be more adaptable to the everydayness of PCOS than datafication of the body. While Sarah Pink et al. argue that the digital and the material are always tightly intertwined into ‘assemblages of humans–technologies–software–data’ (Pink et al. 2017: 3), in Esther’s case the material supplanted the digital as a more workable, meaningful alternative, allowing for more agency over private data.

Other interviews demonstrated that digital-material assemblages can be an integral part of daily life. For Karolina, the everyday home environment includes a variety of objects: balanced meals, plastic-free containers, dumbbells for exercising, her

Figure 1: A period tracker in a bullet journal owned by Esther.



Source: Photo by the author taken on 4 February 2023 in Denmark.

smartphone with the Flo app installed, and, at the time when she was trying to conceive, pregnancy tests, the Flo app's fertility mode, and attentively checked bodily fluids (specifically the 'egg-white' cervical mucus that indicates ovulation). I would call this totality of objects 'digital materiality'. As soon Karolina, as a 20-year-old, heard from her gynaecologist that PCOS makes it harder to conceive naturally, she was determined to be proactive and do everything possible before turning to fertility treatment. Therefore, she ditched her Tupperware to avoid its allegedly harmful effect on egg quality, abstained from coffee and fast carbs to balance insulin levels and thus regulate ovulation, drank enough water to stay hydrated, exercised regularly, and tracked all these activities in Flo. The app, therefore, became a part of the domestic environment of Karolina's suburban home – the repository of what Pink and colleagues call 'mundane data' (Pink et al. 2017).

Yet these data were not simply a reflection of daily routines: they were curated by the user. If Esther refused to track her period in an app altogether, Karolina avoided tracking certain data, namely, negative pregnancy tests. Self-tracking is arguably far from total and continuous self-surveillance: it is a messy and selective practice (Esmonde 2020). Negative pregnancy tests affected Karolina's self-confidence and challenged her self-perception as a prospective mother. Viewing a negative test as a 'mistake', she did not want to record it in the app. While such an omission could be counterproductive for the app's algorithm, it was necessary to maintain the user's mental health. It made the app feel ordinary and familiar rather than powerful and capable of solving the 'mystery' (Polzer et al. 2022) of the body affected by PCOS: 'And it was the thing I had to tell myself every day, that an app is just an app, it's not something that promises you a baby.'

Like Karolina, who did not want to enter negative pregnancy test results into Flo to avoid reminders of her challenged fertility, Alberte felt uncomfortable about her irregular period, regardless of any reproductive plans. Cycles, the app Alberte used, repeatedly sent her erroneous reminders of forthcoming periods, while in fact her periods did not arrive. Alberte described the app as 'such a fragile place'. She explained: 'Because you feel like you're not doing what you're supposed to do (...) Your period is supposed to just be there because you're a woman of a certain age, not 60 or whatever, a 20-something-year-old woman. Why aren't you ovulating? What is wrong with you?' Even outside her reproductive plans, Alberte thus views menstruation as an essential attribute of being a young woman and its absence as something diminishing her womanhood. The app makes the user fragile by constantly reminding her of her 'failure' to fit medical and social gender norms. This story of fragility echoes the negative perception of telecare technologies by people with chronic heart conditions analysed by Nelly Oudshoorn: self-monitoring makes one constantly think of the illness, not only in the clinic but also at home (Oudshoorn 2011: 175–177).

Several interviews revealed that rather than relying on the apps as powerful sources of knowledge about their bodies, women with PCOS tinkered with them: they entered some data and not others, ignored erroneous period predictions, and tried different apps or switched apps during pregnancy (for example, Preglife instead of Clue). Three respondents tracked their periods not in MFTAs but in the inbuilt health apps on their smartphones, such as Apple Health (this was what Diana, Isabella, and Lærke did). These apps, too, can be useful for some purposes but not for others. Isabella shared that she uses Apple Health to detect correlations between her menstrual cycle and physical symptoms such as indigestion or pelvic cramps. However, she was unable to guess the timing of her irregular ovulation. Even expensive ovulation kits were no help because false positive results are common in PCOS, so she ultimately neglected this option.

Some interviewees preferred combining different types of apps – MFTAs, fitness and calorie trackers, and reminders to take medicine – rather than entering all the symptoms or activities in one tracker. MFTAs were most often described as disappointing. For example, Diana tried to enter as much data as possible into Flo to receive accurate predictions of her irregular periods, but she did not achieve the desired result. While she appreciated the educational information on different phases of the menstrual cycle this app offers, Diana was no longer expecting to receive accurate predictions and used the app solely to record her period when it arrived. Rikke found it hard to track her cycle in an app due to her ADHD (attention deficit and hyperactivity disorder) because tracking requires concentration and consistency, which is challenging for someone with this type of neurodivergence. Nanna and Olivia both tried different apps and preferred Clue for a while, but eventually found it not very useful and gave up tracking. Olivia ended up using the Notes app on her smartphone to track her period, which can be described as a digital version of a bullet journal that works outside FemTech and the ‘practices of dataism’ – the practices of gaining insights from adding one’s own data to large data sets (Esmonde 2020: 78).

All in all, the everyday, mundane use of self-tracking apps that my respondents described does not follow the capitalist, market-driven logic of choice. Their typical use pattern is trying various apps in the hope of making sense of a menstrual cycle or conceiving a child, getting disappointed by the result, and abandoning the technology or using it sporadically and selectively, not viewing it as a source of education and empowerment. This finding is contrary to the argument of Didžiokaitė et al. that, unlike the members of the Quantified Self movement (an international community dedicated to actively using and designing self-tracking tools), ordinary users trust the app’s algorithms and do not try to meddle with it (Didžiokaitė et al. 2018: 1478). My respondents, too, are ordinary users, not Quantified Self enthusiasts. However, rather than simply following what the apps suggest they do, these women view the

apps as imperfect but still occasionally and fragmentarily useful. They understand that an app can promise neither a desired pregnancy nor a thorough understanding of one's menstrual pattern, and none of the respondents reported that the apps help them communicate with their doctors. The data women with PCOS produce in their apps is mundane in the sense Pink and colleagues describe it – 'always incomplete', 'ongoing', dependent on the flow of everyday events, which can include feeling certain emotions, having poor digestion, throwing out yet another negative pregnancy test, or deciding not to spend any more money on expensive ovulation test kits (Pink et al. 2017). For a better understanding of their bodies and their unique configurations of PCOS symptoms – or 'symptom packs', as Karolina phrased it – they turn to social media.

Making sense of PCOS online

As I have shown, self-tracking apps are not flexible enough to capture the diversity of symptoms that PCOS patients can have. The irregular menstrual cycles that apps fail to predict correctly is just one possible symptom, and it is not one that all PCOS patients have. Insulin resistance, which is considered a part of PCOS pathophysiology (Panidis et al. 2012), was named as a problem by several of my respondents. To battle this problem and prevent the development of type 2 diabetes, patients can benefit from the use of nutrition and fitness apps, but first of all they need guidance on what diet and exercise plan to follow depending on their vitals, body mass index, relationship with food (whether someone has the experience of an eating disorder), reproductive plans, and so on. In order to make sense of the blood tests, physical and mental sensations, menstrual patterns, and reproductive prospects it is necessary to go beyond private self-tracking and solitary searches for information on PubMed or the websites of Danish and foreign medical organisations.

Above I mentioned the insufficient information that my respondents received from their gynaecologists, GPs, and nurses. For example, when Diana, a Danish woman living in Norway, stopped taking her contraceptive pill at the age of 28, she had only ever menstruated once and had been waiting for a long time for her next period to come. Concerned, she turned to a gynaecologist, but this doctor refused to perform an ultrasound: 'She said, well, yeah, I don't think you have PCOS. You don't look like anyone who has PCOS.' Diana had to convince the doctor to perform the ultrasound, and as a result, she received a PCOS diagnosis but no good advice: 'I think she just wanted to get me out of the room.' Similarly, Johanne, a 27-year-old woman with several chronic illnesses undergoing fertility treatment, told me that it was hard to communicate with her doctors. She doubted that 'they have the empathy for this feeling of multidimensional disease and a lot of things going on mentally and physically'.

When Isabella received her PCOS diagnosis at the age of 18, she had many questions for her gynaecologist:

I was just like, okay, what's wrong with me? What can I do? What can I do in the future? And all he said back to me then was, 'If you want children, we can help you.' And then I said to him, But what can you do now? Because I'm 18. I'm, I'm in school. What can you do for me now? (...) And I said if you can't do anything now then I'm just about to leave, because his focus was only on, you know, getting me pregnant at [laughs] 18 years old.

Isabella therefore turned to Google and social media for information.

For Diana, Isabella, Johanne, and others in my fieldwork, social media offered the opportunity to be heard and seen with their different symptom packs and needs, whether those needs were improving their diet, figuring out what the results of certain blood tests meant, or discussing postpartum recovery – because, as Rikke put it, 'PCOS doesn't stop when you've had kids'. Offline support groups are almost non-existent. For example, Nanna told me about PCO Foreningen (Polycystic Ovaries Association), an organisation for women who have PCOS and polycystic ovaries but not enough symptoms to receive a PCOS diagnosis. For a while, PCO Foreningen arranged meetings in different regions in Denmark, but it ceased operating several years ago, and its website is inactive. Nearly all my respondents are members of private Facebook groups dedicated to PCOS.

Similarly, almost all the respondents told me that they follow doctors specialising in PCOS and expert patients on Instagram, TikTok, and YouTube. These public social media pages provide fewer opportunities for discussion and dialogue because any comments under the influencers' posts are visible to the broader public, which my respondents often find discouraging. The most frequently cited Danish Instagram page on PCOS 'Cysterskab' (a wordplay analogous to the English 'cysterhood', popular in PCOS communities) has very few comments under its posts (@cysterskab), but the influencer who runs this page also manages a private forum. According to many of my respondents, discussions in this forum are active and useful even for those who are reluctant to participate. I chose not to have access to this forum for two reasons. First, if I wanted to analyse the comments and discussions posted there, I would have to deal with the complicated ethical and legal issue of obtaining GDPR-compliant consent from participants. As Gammelby explains in her study of patient support groups on Facebook, if a researcher occasionally looks at some participants' comments, telling these participants about the research and the need for consent according to GDPR can feel 'disproportionally invasive' (Gammelby 2021: 128–139). Respecting the privacy of participants in the 'Cysterskab' forum, I found it more ethically appropriate

to rely on my interviewees' narratives about their use of this forum. It is not my aim to examine how they actually use the forum. Instead, I am interested in their impressions of and feelings about this digital space. Similarly, I abstained from joining any PCOS support groups, except for the one that I used to recruit participants and to get a general idea of its posts and discussions.

The distinction between public and private on the Internet is problematic: it is not defined by a division of space, and even the private status of Facebook support groups or password-protected forums does not guarantee that shared personal information is protected (Bennett 2011; Lupton 2012: 238–239). However, my interviews revealed that the desire to find relatable stories (or 'illness biographies', as Kragh-Furbo and colleagues call them) outweighs privacy concerns (Kragh-Furbo et al. 2018: 58). Esther admitted that a forum for PCOS patients makes her 'feel less alone' and provides answers to her questions about personal symptoms and needs. She finds it useful that other participants often share and discuss their blood test results. Paula, quoted at the beginning of this article, liked having the opportunity to share her frustration about unwanted body hair in support groups on Facebook: 'There's someone you can complain to and they *know* what you're talking about.'

Sharing private 'biosensor data' can be conceptualised as a 'sense-making activity', even if these data were gathered not by the patients themselves on personal m-health devices but by their doctors, as in the case of my interviewees (Kragh-Furbo et al. 2018: 57–58). Blood test results, diets and recipes, medications to lower blood sugar, birth control pills to mitigate menstrual pain and irregularity, and remedies for body and facial hair – all this is discussed in online communities. Like the members of the patient forums analysed by Kragh-Furbo and colleagues, participants in PCOS-themed Facebook groups and forums 'together attempt to make sense of their bodies' by engaging in 'conversations based on speculation, hypothesis and personal experiences' (Kragh-Furbo et al. 2018: 49, 57). They also share advice about doctors who are knowledgeable in PCOS and about the best reproductive clinics, as well as information about clinical trials of medicines for PCOS, such as SPIOMET4HEALTH, in which three of my respondents volunteered to participate (<https://spiomet4health.eu/>).

To be precise, online communities do not necessarily provide a full sense of acceptance and relatability. Patients with less common phenotypes, such as those with regular cycles or leaner bodies, find it harder to relate to other participants. Feeling like a 'non-typical' PCOS patient can discourage a person from joining online communities. This was, for example, Olivia's situation: when trying to conceive, she read a lot about PCOS on the Internet and could not find relatable information on medical websites: 'I felt like I didn't fit in any of the boxes that were described or any of the other symptoms that were described. So maybe I felt like, "What's the point of talking to other people?" Because what helped them is probably not going to do anything for me.'

At the same time, patients who feel like they are a 'special case' may be driven to join a community because they know PCOS is 'multidimensional' and that, therefore, the odds are that they will find people with similar phenotype profiles on social media. Furthermore, as I mentioned, the empathy sought by members of PCOS-themed groups and forums can come from people with different 'symptom packs' and experiences. For example, Johanne, a woman with a smaller body, expressed her empathy for people with larger bodies who are fat-shamed by their doctors. She also remarked that 'a lot of people write really nice things' in online communities when she shares feelings of sadness and loneliness.

If for Johanne online communities are first and foremost a source of emotional support, others have more practical goals. Veronica collects information in English-language Facebook groups and explores it further through a Google search: this is her mode of sense-making. When Nanna failed to find enough discussion about becoming pregnant after undergoing a fertility treatment specifically for women with PCOS, she launched a Facebook group on this subject and later another group about postnatal experiences. That is, she aimed to fill a gap on social media to help people with experiences similar to her own to make sense of them. Veronica admitted that for her it was important to see that there were other people with even worse experiences with facial hair or acne treatment who were nonetheless brave enough to share their pictures online. Mie made a similar comment: 'I saw a lot of people online, like on Instagram and TikTok, who were on the same pill [systemic retinoids] that I was, and I saw the way they were experiencing [dryness and redness of skin], which was a lot worse than me.'

Whatever way PCOS patients choose to use social media, my interview data indicate that doing so helps them to make sense of their body better than self-tracking apps do. The access to the private details of others allows them to feel less alone and gives them clues to interpret their own specific symptoms, such as evaluating the degree of facial hair growth or, in the case of lean PCOS patients with insulin resistance, collectively looking for the best nutrition plan. By communicating in provisionally 'private' digital communities, patients are not simply consuming data provided by state medical labs (as in the case of the bloodwork ordered by their physicians) or generated by self-tracking apps. Instead, they are taking a critical approach to these data and helping each other to interpret them.

Caring through sharing

From the thematic analysis of my interview data, I conclude that social media tend to be more helpful for women with PCOS than self-tracking apps in understanding their bodies and symptoms. I explain this difference through Annemarie Mol's theory of

different logics in healthcare. I have already argued that self-tracking apps follow the capitalistic logic of choice, where autonomous individuals choose to input their 'lively data' and thus control their well-being. However, PCOS bodies, which have diverse irregularities and defy gender norms, escape this logic. Social media communities operate according to a different logic, the logic of care, which, as Mol explains, involves constant tinkering and adjustment. Instead of assigning individuals with full responsibility for their health and making the best consumer choices, care involves negotiations between patients and their doctors, nurses, and significant others in the search for workable solutions. These solutions are not directed at curing the patient – because PCOS, like many chronic diseases, is incurable – but at achieving an experience of daily life that is good enough and bearable, with minimal pain, moderately good blood sugar levels, a blood pressure that is not too high, and so on (Mol 2008: 14–27).

My interview data suggest that PCOS-themed Facebook groups and forums operate according to the logic of care in three ways. First, they acknowledge the chronic character of PCOS and provide long-term support through continuous posting and discussions. Online communities can help their participants to keep trying to mitigate their symptoms without promising to eliminate them. Mol explains: 'But the fact that health is out of reach does not mean that you should give up.' (Mol 2008: 32) For example, Alberte once posted a question on a forum about when and how to tell a man you are dating about your reproductive health problems. This was a question that acknowledged possible long-term difficulties that cannot be avoided and, therefore, had to be shared with a prospective romantic partner.

Second, as I argued in the previous section, the groups allow for the discussion of diverse 'symptom packs', needs, priorities, and goals. To be sure, groups tend to focus on some issues more than others, such as weight loss or trying to conceive. As a result, patients with smaller bodies (the 'lean PCOS phenotype', explained, for example, in Goyal, Dawood 2017), like Karolina and Johanne, or child-free people, like Lærke, found it harder to encounter relatable stories. Therefore, the care online communities provide is not necessarily straightforward and universally applicable. However, according to Mol and her colleagues Ingunn Moser and Jeannette Pols, care can never be perfect, it can only be 'good enough' (Mol, Moser, Pols 2010: 13). It may take more time and effort to find fellow PCOS patients who have smaller bodies, more regular menstrual cycles, or without an interest in reproduction, but it is not impossible. You can post about your specific problems and attract participants with similar 'illness biographies'. Or, like Nanna, you can launch a new group, dedicated to a specific subcategory of PCOS. This is how the logic of care deals with the dilemma of 'the individual vs the collective'.

I can think of Danish women with PCOS as a collective that consists of individuals with different symptom packs, needs, and goals, or I can identify various sub-collec-

tives, such as 'lean' or 'child-free' PCOS patients, who need different kinds of care. Mol explains that the logic of care starts with collectives rather than individuals. These collectives are defined by the particular circumstances in people's lives, their habits, and their immediate social circles. The general guidelines for PCOS treatment are not universally applicable: each subcategory, or collective, needs its own solutions in terms of, for example, diets, exercise, regulation of menstrual cycle, facial hair removal, or management of fatigue or cravings. 'The character of the collectives that are relevant to care is not given but somehow needs to be established.' (Mol 2008: 68) Online communities, I suggest, serve as arenas for establishing the character of different collectives of PCOS patients. If the logic of choice that defines m-health technologies views patients as autonomous individuals, the logic of care 'is attuned to people who are first and foremost related' (Mol 2008: 72). Online communities facilitate relations between those who suffer from or successfully manage (though do not eliminate) similar PCOS symptoms.

Third, the members of online communities relate to each other by sharing their stories. Their posts and comments can be viewed as storytelling or as narrating 'illness biographies'. While Mol, in her study of the logic of care, focuses on medical settings, she recognises that through stories, care moves outside the doctor's consulting room to journalist reports and social scientists' papers, as well as to patients' daily lives. In Mol's case study, Dutch patients with type 1 diabetes told stories to 'their relevant others, their relatives, their friends'. These stories differ from arguments (which are used in clinical research and marketing) in that they allow for diverse interpretations. 'While sound arguments should be clear and transparent, powerful stories work by evoking people's imagination, empathy and irritation. While conflicting arguments work against each other, conflicting stories tend to enrich each other. And while adding up arguments leads to a conclusion, adding stories is more likely to be the way of raising even more questions.' (Mol 2008: 88)

My interviews demonstrate that reading unrelatable stories can be difficult. 'I just got so discouraged about all the stories that I didn't see myself in', Diana admitted. Unrelatable stories raise questions such as: if others can make their menstrual cycles more regular by losing weight, what can you do if you already have a small body and losing more weight could be bad for your health (Karolina)? How to remember to take birth control pills for menstrual regularity if your ADHD makes it hard to remember about (Rikke)? Or how to manage fertility treatment emotionally if your cardiologist believes that it could be dangerous for you given your chronic heart condition co-existing with PCOS (Johanne)?

Nevertheless, patients can keep telling stories even if they do not meet anyone online with a similar experience and at least find empathy from people who try to relate to them. They can create new communities for telling such stories, just as Nanna did

when she was pregnant and then became a mother while still struggling with PCOS symptoms. Or they can tell stories offline, like Rikke, who chairs an ADHD foundation and talks about her PCOS at its face-to-face meetings. Sense-making can transcend the boundaries between the Internet and the tangible world, between private and public. As Mol argues, 'Public life deserves to be infused with rich stories about personal events. Private events should not be hidden behind the desire to be free' (Mol 2008: 102). Stories about personal events can be more relatable or less relatable, but if patients keep telling them, everyone gets a chance to make better sense of their lives with PCOS.

Self-tracking devices are designed for individuals who want freedom and privacy to manage their physical and mental health. In exchange, however, they require self-surveillance. They present data, to use Mol's expression, as 'clean, contained and unemotional, far removed from the messy contingencies and uncertainties of the body and its ills and the distressing or unsettling emotions associated with these'. Online communities, conversely, offer stories about uncertainty. In the case of PCOS, these can be stories about, for example, messy menstrual patterns, confusing hormone levels, or uncertainty about the best diet for preventing diabetes. Telling private stories is a 'form of public coordination' (Mol 2008: 102). By telling stories, members of PCOS-themed online communities collectively navigate diverse questions, define the characteristics of collectives with different symptom packs, and thereby offer continuous care without promising any perfect outcomes.

However, the logic of choice and the logic of care do not necessarily need to be in sharp opposition. The socio-material networks of biosensing can accommodate both types of logic. While my respondents turned to social media to share stories and ask for advice, they kept making individual choices about which influencers to follow, which websites to visit for up-to-date medical information, and which products to consume for managing PCOS, be it a gym membership or a book of PCOS-friendly recipes. Just like the use of self-tracking apps, participation in online communities can be selective. At different stages of one's life, either the logic of choice or care can make more sense and be preferred.

Furthermore, care is not devoid of power inequalities. While scholars advocating a 'feminist ethics of care' frame care in opposition to neoliberalist individualism and associate care with global solidarity (Kittay 2011; Robinson 2015), the notion of care can also be used to mask inequalities. Michelle Murphy, in her analysis of the political discussions of care in the 1970s, criticises these discussions' reliance on 'white privilege, capitalism, and postcolonial humanitarianism' (Murphy 2015: 720). In the case of Danish PCOS support groups and forums, I can assume they are predominantly made up of white, middle-class, cisgender heterosexual women, whose concerns and opportunities define the topics of the discussion threads. The fact that most of my

respondents belong to this category confirms this assumption.⁵ People with PCOS who are from marginalised groups would feel less safe in such online communities, not least, presumably, because of privacy concerns. Therefore, I am not suggesting that social media can make up for the shortcomings of the capitalist logic of choice and produce a perfectly inclusive sisterhood. Nonetheless, I hypothesise that online communities have the potential for what Murphy calls ‘unsettling care’ – applying critical tools to problems that already exist, ‘reckoning with a world already violated’ (Murphy 2015: 732). Sharing more stories about PCOS as experienced in different cultural, social, and political contexts, shaped by different economic conditions, can make care more flexible, inclusive, and effective.

Conclusion

This article offered a theoretical analysis of digital technologies used by women with PCOS, a complex chronic medical condition. My analysis of the interviews showed that at least some women with a PCOS diagnosis can engage with digital technologies to make sense of their symptoms and identify their needs. I focused on two types of technologies: self-tracking apps and online communities. I argued that self-tracking apps follow the capitalist logic of choice based on the idea of the autonomy of the individual – for example, of an empowered woman who knows her body very well through consumer technology. Online communities operate according to the logic of care and rely on the sharing of personal stories to find collective solutions. But rather than presenting the two types of logic in sharp contrast, I suggested that PCOS patients constantly navigate between them. The examples from my interviews often demonstrate the simultaneity of the wish to self-sustain through FemTech products and the drive to show solidarity and share advice. If a menstrual tracker annoys patients with irrelevant notifications, they can abandon it in favour of a bullet journal. An influencer on Instagram or TikTok can inspire patients to choose themselves how to treat their symptoms instead of following the generic advice from their doctor. However, if their choices do not produce the desired result, they can find a Facebook group or a forum in which to share their frustrations, or they can even organise a new online community. Digital technologies can be a source of despair because PCOS is stubborn, incurable, and impossible to explain via self-tracking apps. But these technologies can also bring one closer to people with similar despair who can empathise

⁵ My limited command of spoken Danish limited my choice of respondents to those with strong English proficiency, that is, well-educated middle-class women. Even though the average level of English proficiency among young Danes is quite high (EF 2024: 18), I assume that people with higher education are more confident communicating in English with an interviewer.

and offer possible solutions, and if these solutions do not work, they can all collectively look for alternatives. The capitalistic logic of choice that defines self-tracking apps and other FemTech products can be frustrating for women with PCOS. Still, these products are not necessarily useless: my respondents gave examples of their instrumentalising them as just one component of their sense-making.

In navigating between the logic of choice and the logic of care patients are blurring the boundaries between private and public. The everyday management of PCOS encompasses the privacy of home, the relative privacy of online communities, and the publicity of social media accounts by medical influencers and expert patients. The private, semi-private, and public spaces of everyday life with PCOS comprise ‘socio-material networks of biosensing’ (Kragh-Furbo et al. 2018: 267–268). A PCOS patient, for example, can simultaneously keep some of their symptoms out of self-tracking apps and share them instead with virtual strangers in a Facebook group or post a photo of their facial hair before shaving it in order to feel more confident in an offline meeting of a mental health support community. Publicity and privacy exist and fuse in the everyday reality of PCOS, just like the practice of digital self-surveillance interweaves with mutual caring through sharing in online communities. A woman with PCOS is not a self-sustained, autonomous individual, but a member of numerous collectives in which technologies find multiple uses.

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