

CONTROLLING THE MONSTER: EXPLORING CONSTRUCTIONS OF WOMEN AND
THEIR BODIES IN ENDOMETRIOSIS APPS

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Abstract

People globally increasingly use digital applications (apps) to manage their health and health conditions. In particular, women commonly use apps to understand and manage female reproductive issues. Some apps target women with endometriosis, a common but poorly understood condition primarily affecting women. The aim of the current research was to explore how endometriosis apps constructed endometriosis and people with endometriosis, how people with endometriosis were positioned, and the potential implications of this positioning for app users. Multimodal critical discourse analysis (MCDA) was used to systematically examine dominant meanings produced by visual and linguistic features (i.e. colour, imagery, text and interactive app functionality) of five endometriosis apps from the USA, New Zealand and Singapore. Results demonstrated that apps drew on biomedical and biological discourses to construct endometriosis as a complex and confusing disease of the female reproductive body. This positioned biomedical and natural health professionals as knowledgeable experts about endometriosis while minimising women's experiential knowledge of their bodies. Apps drew on intersecting postfeminist, neoliberal and healthist discourses to construct women with endometriosis as responsible for self-tracking many physical, emotional and behavioural experiences. Self-tracking was constructed as generating data that was meaningfully interpreted by app algorithms and experts to help women understand and manage their endometriosis. Dominant management recommendations (i.e. biomedical interventions; lifestyle changes) aligned with hegemonic ideals of traditional and neoliberal femininity. These findings align with previous feminist research findings that mainstream endometriosis discourse reflects androcentric biases in medical knowledge and that health apps targeting women often reinforce neoliberal and postfeminist ideals. Therefore, dominant discourses about endometriosis and female biology that pathologise women's bodies and behaviours limit the potential for apps to offer women empowered and agentic subject positions.

Keywords: endometriosis; digital health technology; multimodal critical discourse analysis (MCDA); health psychology; postfeminism; self-tracking

Table of Contents

Acknowledgements.....	2
Abstract.....	3
List of Tables	6
List of Figures.....	7
1 Women, Endometriosis and the Biomedical Paradigm	8
1.1 Women’s experiences of endometriosis	9
1.2 Inadequacy of medical support for women with endometriosis	11
1.3 Medical and scientific endometriosis knowledge.....	12
2 The Digital Health ‘Self-Management’ Industry and Women’s Health Apps	16
2.1 Coping with and managing endometriosis	16
2.2 Self-management using health and medical apps.....	17
2.3 Social and cultural implications of women’s health apps	19
2.4 The current study: aims, theoretical framework and research questions.....	21
3 Method.....	26
3.1 Analytical approach.....	26
3.2 Research considerations.....	28
3.3 Procedure	31
3.4 Description of apps	35
4 Endometriosis: A Disease of the Female Reproductive Body.....	41
4.1 Constructing endometriosis as a disease of the female reproductive body	41
4.2 Privileging biomedical and scientific knowledge about endometriosis	58
4.3 Pathologising women’s bodies and behaviours.....	60
4.4 Summary.....	62
5 Endometriosis as Confusing and Bad: Motivating Users to Self-Track.....	64
5.1 Constructing endometriosis as inherently complex and confusing	64

5.2	Constructing endometriosis as severe and all-encompassing.....	74
5.3	Pathologising excessive negative emotionality	82
5.4	Encouraging self-tracking.....	85
5.5	Summary	90
6	‘Controlling’ Endometriosis: Creating Healthy, Feminine, Neoliberal Subjects	91
6.1	Self-managing endometriosis through medicine, behaviour and nutrition.....	91
6.2	Self-managing endometriosis is essential for being ‘healthy’	103
6.3	Becoming a ‘healthy’ woman with endometriosis	107
6.4	Summary	120
7	Discussion and Conclusions	121
7.1	Key findings and implications for users	121
7.2	Limitations and reflections on this research	129
7.3	Looking forward.....	133
7.4	Concluding comments	136
	References.....	138
	Appendix A. Endometriosis apps not in sample.....	165
	Appendix B. Summary of codes	166
	Appendix C. Additional details of app listings in Apple App Store.....	168

List of Tables

Table 137

List of Figures

Figure 1.....	36
Figure 2.....	43
Figure 3.....	44
Figure 4.....	46
Figure 5.....	48
Figure 6.....	54
Figure 7.....	56
Figure 8.....	59
Figure 9.....	69
Figure 10.....	80
Figure 11.....	81
Figure 12.....	83
Figure 13.....	86
Figure 14.....	87
Figure 15.....	89
Figure 16.....	93
Figure 17.....	95
Figure 18.....	98
Figure 19.....	106
Figure 20.....	109
Figure 21.....	112
Figure 22.....	115
Figure 23.....	117
Figure 24.....	119

1 Women, Endometriosis and the Biomedical Paradigm

“Endometriosis has been known as the ‘silent disease’, but that isn’t because women don’t want to talk about it” (Jackson, 2019, p. 5).

This quote comes from Gabrielle Jackson’s (2019) book *Pain and Prejudice: A Call to Arms for Women and their Bodies*, written after Jackson published an online feature about her experience with endometriosis. Endometriosis is a condition thought to affect an estimated 10 percent of women globally; it is typically understood as being characterised by endometrial-like tissue causing lesions and inflammation outside the uterus (Rogers et al., 2017). In her original feature, Jackson wrote about suffering from common endometriosis symptoms such as “debilitating” dysmenorrhea (pain during menstruation), back and leg aches, nausea, digestive problems, bloating, a poor immune system, lethargy and fatigue (Adamson, 2012). Jackson’s doctors in Australia ignored her concerns about her dysmenorrhea for eight years and failed to link her other symptoms to endometriosis for another fourteen years (Jackson, 2015).

Upon reading Jackson’s feature, women around the world shared their own stories about living with endometriosis with *The Guardian* (2015). A Portuguese woman wrote that “[the pain] is entirely overwhelming. It feels like someone is pulling a big knife around inside my belly”, while other women spoke of difficulties conceiving and carrying pregnancies to full-term, managing family and partner relationships, and meeting work and social obligations. Women commonly described other people forcing them to stay silent about their suffering, summed up by a woman from Bulgaria who reflected: “I was told that it was normal, that periods hurt a lot...My life was affected in many ways because no one understood how I felt”. Understanding more about how women with endometriosis can experience better outcomes is the driver for undertaking this research.

1.1 Women's experiences of endometriosis

Academic research into the physical and psychosocial impacts of endometriosis supports these women's stories. Survey-based studies show that endometriosis-related pain and other symptoms reduce women's quality of life (Tripoli et al., 2011), their ability to perform daily life activities, exercise, have sex, do household chores, care for children, and socialise (Bernuit et al., 2011; Fourquet et al., 2010). Women with endometriosis commonly report significantly lower mental health and wellbeing than women without endometriosis: an endometriosis diagnosis is correlated with higher stress levels (Petrelluzzi et al., 2008; Siedentopf et al., 2008), anxiety and depression (Fourquet et al., 2010; Laganá et al., 2015), and lower levels of subjective wellbeing (Rush & Misajon, 2018). Although these studies were conducted primarily on adult White women in high-income Western countries, studies conducted in non-Western countries (Nnoaham et al., 2011), on non-White women and on adolescents (Gallagher et al., 2018) have found similar patterns. Findings from these survey and psychometric studies paint a picture of endometriosis as an often painful, debilitating condition that can affect many areas of women's physical and psychological lives.

Researchers have also used interview-based research to understand women's experiences of endometriosis. Women typically report difficulties managing their endometriosis symptoms leading to reduced quality of life (Cox et al., 2003; Moradi, Parker, Sneddon, Lopez & Ellwood, 2014; Roomaney & Kagee, 2018), living with chronic pain (Hållstam, Stålnacke, Svensén, & Löfgren, 2018), and reduced work and social participation (Huntington & Gilmour, 2005). Denny (2004; 2009) conducted interviews with women in the United Kingdom (UK), finding that women considered endometriosis-related pain more intense, enduring and pervasive than 'normal' period pain, and were worried about how their pain would affect their work, relationships and ability to have a family. Moradi and colleagues (2014) interviewed Australian women of different ages who described

endometriosis pain as “‘sharp’, ‘stabbing’, ‘horrendous’, ‘tearing’, ‘debilitating’ and ‘breath-catching’” (p. 4), and reported that endometriosis negatively impacted their intimate relationships, social life and physical and psychological health. Roomaney and Kagee (2018) reported that endometriosis was a central feature of life for women in South Africa, as it negatively impacted their physical, psychological, sexual, reproductive, interpersonal, and occupational functioning.

This body of qualitative interview research also offers insight into how endometriosis symptoms affect women’s social and cultural lives. For example, symptoms like dyspareunia (painful sex) and infertility can negatively impact women’s intimate partner relationships. Women described feeling pain during and for days following sex (Mellado et al., 2016; Seear, 2009c), and often felt too tired, stressed or unattractive to be intimate (Hudson et al., 2016). Women often coped by enduring pain during sex or avoiding sex, and described feeling guilty and inadequate for being unable to participate in the type of sexual activity that they or their partners want (Denny & Mann, 2008). Some studies reported that endometriosis-related sexual problems had contributed to relationships ending (Denny, 2004; Mellado et al., 2016; Seear, 2009c). Other studies found that fertility issues strained intimate partner relationships: for example, women from certain minority ethnic communities in the UK (i.e. British South Asian, Chinese, and African Caribbean) were concerned that infertility would lead to relationship breakdown, due to cultural expectations that women reproduce (Denny, Culley, Papadopoulos & Apenteng, 2011; Hudson et al., 2016). These examples demonstrate how women are often required to navigate complex relational challenges caused having a condition that compromises her ability to conform to socially and culturally prescribed roles.

In summary, a substantial body of research demonstrates that women find endometriosis challenging. More research is needed to understand the experiences of people who are not White, heterosexual, middle-class, adult, cisgender women living in wealthy

Western countries (Gallagher et al., 2018). In fact, Jones (2016) wrote that “women of colour, poor women, and queer women have nearly been erased from endo discourses altogether” (p. 563). Nonetheless, the evidence supports Jackson’s (2019) assertion that women are not silent on the topic of endometriosis. Jackson argued that it is the medical establishment that often silences women: “sufferers from around the world faced the same battles: long delays in diagnosis, having their pain doubted then normalised, having their mental health questioned and receiving bad medical advice” (p. 5). This raises the question: why does medical support for women with endometriosis globally fail to incorporate the knowledge we have about women’s experiences?

1.2 Inadequacy of medical support for women with endometriosis

Many women report encountering significant problems when seeking help from medical professionals about endometriosis. There is a well-documented delay between onset of a woman’s symptoms and receiving an endometriosis diagnosis globally. Nnoaham and colleagues (2011) identified delays in ten countries, ranging from 3.3 years in China to 10.7 years in Italy. The authors highlighted that delays were significantly longer in countries with state-funded healthcare compared with countries requiring self- or insurance-funded healthcare. They (and others) argued that this discrepancy is caused by general practitioners (GPs) being slow to refer women to specialist gynaecology services (van der Zanden, 2019).

Many other studies reported that GPs normalised, trivialised or disbelieved women’s symptoms, especially pain (Denny, 2004; Denny & Mann, 2008; Whelan, 2007). Ballard, Lowton and Wright (2006) found that British women identified delays at both the personal and the medical level when seeking support for endometriosis. Women delayed seeking help because they assumed their pain was normal and because social stigma about menstruation stopped them discussing their symptoms with others. Women also reported that when they

did seek help, GPs advised them that their menstrual pain was ‘normal’, prescribed hormones that only temporarily suppressed symptoms, and relied on investigations that did not discriminate between endometriosis and other diagnoses. Other studies found that GPs were more willing to refer women to gynaecologists when they experienced difficulty conceiving, or for endometriosis symptoms other than pain such as gastrointestinal problems (Jones et al., 2004; Markovic, Manderson & Warren, 2008; van der Zanden, 2019).

The diagnostic delay has material and psychological implications for women with endometriosis. Medicine is a source of authoritative knowledge in modern society (Zola, 1972), so receiving an endometriosis diagnosis from a medical doctor legitimises a person’s suffering, allows access to the ‘sick’ role, and opens up potentially helpful treatment and intervention options (Denny & Weckesser, 2020). The women interviewed in Ballard and colleagues’ (2006) study explained that receiving a diagnosis helped them to understand their experience, opened up treatment options and legitimised their suffering in the eyes of employers and friends. Delays in receiving an endometriosis diagnosis and general negative treatment within medical systems can contribute to women feeling angry, anxious, depressed, isolated and alienated (Seear, 2009c). In response, healthcare systems in Europe (Dunselman et al., 2014), the UK (NICE, 2017), Australia (Department of Health, 2018) and New Zealand (Ministry of Health, 2020) have started trying to improve how medical professionals identify and diagnose endometriosis. While these guidelines represent a positive step toward improving the healthcare experiences of women with endometriosis, they also indicate that the issue remains unresolved.

1.3 Medical and scientific endometriosis knowledge

Women’s experiences of inadequate and harmful healthcare for endometriosis may be partly explained by the fact that endometriosis is poorly understood and highly contested

within biomedicine (Denny & Weckesser, 2020). There is ample evidence challenging traditional conceptions of endometriosis as a gynaecological and menstrual problem. Endometriosis is typically found in the pelvic region, but also occurs throughout the entire body (Lemaire, 2004; Machairiotis et al., 2013), in non-menstruating cisgender women (Manero et al., 2009; Ayuso, Fadare & Khabele, 2013), transgender men (Fox, 2014), cisgender men (Fukunaga, 2012; Jabr & Mani, 2014; Rei, William & Feloney, 2018) and female infants (Schuster & Mackeen, 2015). In fact, endometrial cells and tissue are found in the pelvises of most females, suggesting that their presence alone may not indicate pathology (O et al., 2017). More recent theories argue that endometriosis symptoms occur when autoimmune, hormonal and/or genetic dysfunction interacts with the extrapelvic endometrial tissue, although there is no consensus (Gupta et al., 2015). The presence of endometrial-like tissue also poorly correlates with severity of symptoms, meaning that people with severe endometriosis (in biomedical terms) may be asymptomatic and vice versa (Gupta et al., 2015). In a review of the literature, Whelan (2009) found that there is no academic consensus about how to ‘know’ about endometriosis knowledge.

Many feminist scholars argue that the contradictions in endometriosis knowledge are a consequence of sexist conceptualisations of women that permeate biomedicine and science (Jones, 2015; Seear, 2014). These analyses draw on broader feminist arguments that medicine is an inherently androcentric discipline that has historically understood women and their bodies to be deviant, uncontrollable and threatening to social stability (Ehrenreich & English, 1973; Nash, 2014; Ussher, 2006). In general, these scholars argue that endometriosis threatens medical claims to knowledge and control over the female body, which medicine deals with by pathologizing women’s biology, personalities and behaviours. For example, Shohat (1992) highlighted how biomedical discourse constructs endometriosis in terms of

excess menstruation and ‘feminine’ emotionality, reflecting cultural beliefs that menstruation is abnormal and abject, and that women lack control of their bodies.

Similarly, Jones (2015) and Nezhat, Nezhat and Nezhat (2012) discussed how medicine historically constructed the uterus (for which there is no male counterpart) as an unruly, volatile organ that controlled the female body and wandered about the body if women did not reproduce. They argued that doctors have often used the ‘wandering womb’ concept to literally and symbolically explain female illnesses, such as hysteria in the 19th century, and more recently, endometriosis. Jones discussed how hysteria started as a biological problem of a diseased uterus and menstrual irregularity but became a catch-all diagnosis that male doctors applied to any women who demonstrated symptoms they were unable to control, or personality and behaviours that were ‘unfeminine’. Jones argued that diagnosing women with hysteria (such as wealthy, young and single women, women with careers, and widowed and divorced women) functioned to pathologise and discipline women who did not comply with their socially prescribed roles of heterosexual marriage and motherhood.

Dominant beliefs about endometriosis demonstrate how medicine still pathologises women’s bodies and behaviours. Endometriosis is considered more prevalent in highly educated, employed women who “delay childbearing” (Jones, 2015), and doctors persist in recommending pregnancy as a treatment for endometriosis despite evidence it does not work (Young, Fisher & Kirkman, 2018). Young and colleagues (2018) also found that doctors tended to dismiss women’s experiential knowledge as subjective and therefore less valid, saw women with endometriosis as prone to catastrophising their symptoms and blamed women who continued to experience symptoms and/or seek care following treatment. The biomedical and scientific endometriosis literatures are replete with researchers using correlational studies to argue that women with endometriosis are more neurotic, perfectionist, and irrational (Olive, 2005), anxious and pessimistic (Facchin et al., 2016), and more prone to

catastrophising than other women (Grundström et al., 2016; Martin, Johnson, Wechter, Leserman, & Zolnoun, 2011). These examples demonstrate how medical and scientific endometriosis knowledge is shaped by social and cultural ideas about women more than by women's experiences, and positions women as responsible for contributing to their endometriosis, and for fixing it.

In summary, this chapter has argued that medical knowledge and practice is inadequate to meet the needs of women with endometriosis. Despite the well-documented challenges that women with endometriosis deal with across multiple areas of life, engagement with medical professionals is characterised by confusion, normalisation and dismissal of women and their experiences. In the next chapter, I explore how these factors contribute to women with endometriosis seeking knowledge, advice and support from other sources, including to help them manage their symptoms themselves.

2 The Digital Health ‘Self-Management’ Industry and Women’s Health Apps

In this chapter, I discuss how women employ coping strategies to manage endometriosis-related symptoms and distress. Self-management constitutes an important and understudied type of coping strategy, particularly in the broader context of digital health apps encouraging self-tracking and management for women in particular. I review the literature about potential benefits and concerns associated with women’s health apps, such as how they reflect neoliberal, healthist and gendered values. Following this, I describe how apps can be viewed as visual and sociocultural objects that convey social and cultural norms, values and beliefs (Bivens & Hasinoff, 2018). I conclude by outlining the critical realist, feminist theoretical framework I employed in this research and my research questions.

2.1 Coping with and managing endometriosis

Women cope with endometriosis using a range of non-medical behavioural, cognitive and emotional strategies (Zarbo et al., 2018). Roomaney and Kagee (2016) grouped South African women’s reported coping strategies (collected via semi-structured interviews) into two broad categories. Women used ‘problem-focused strategies’ to manage endometriosis symptoms, such as ‘self-management’ behaviours (i.e. analgesic pain relief, home remedies, heat, and relaxation exercises), limiting physical activity, scheduling activities around their menstrual cycle, and relying on social support from family members. Women used ‘emotion-focused strategies’ to mediate their experience of endometriosis, such as acceptance, adopting a more positive attitude, using more positive self-talk, and drawing on their spirituality. Other studies identified similar strategies, although with some differences: a British study found that women often avoided taking strong doses of analgesic pain relief because they became drowsy and unable to function effectively (Grogan, Turley & Cole, 2018), and women from New Zealand reported increasing physical activity to relieve pain (Huntington & Gilmour,

2005). A large Australian survey similarly found that three quarters of women used ‘self-management’ strategies like heat, rest, meditation, breathing exercises, cannabis, cannabidiol (CBD) oil, and dietary changes (Armour, Sinclair, Chalmers & Smith, 2019).

The internet has afforded women with endometriosis new avenues for accessing information and support. Women have created an ‘endometriosis patient community’ that interacts via websites, support groups, and self-help organisations to share knowledge, self-management options, and reduce their feelings of social isolation (Grogan et al., 2018; Neal & McKenzie, 2011). Whelan (2007) and Shoebottom and Coulson (2016) described how this community has formed a collective identity around their shared experience of endometriosis and privileges women’s experiential knowledge in ways that biomedical knowledge and doctors often do not. Women in the UK and US who participated in online support groups reported feeling more empowered to advocate for themselves in medical encounters and to manage on their own using self-management techniques (Shoebottom & Coulson, 2016). However, other research suggests that women with endometriosis can find self-management to be “burdensome and excessive, as well as practically impossible, time-consuming and too expensive” (Seear, 2009a, p. 367). Therefore, more research into contemporary digital self-management strategies for endometriosis is needed.

2.2 Self-management using health and medical apps

The rapidly growing digital health industry continues to offer new digital health technologies for managing health beyond websites and online support groups; the industry now includes more sophisticated technologies such as health applications (apps; Lupton, 2017). Apps are pieces of software that can be downloaded to mobile devices (e.g. smartphones and tablets) that enable people to access, create and share information wherever they are (Lupton, 2017). Typically, health apps encourage users to seek health-related

information, connect with others and generate their own information and data (Sanders, 2016). App functionality ranges from basic pages offering users health-related information to sophisticated tracking of biometric data collected by linking with wearable tracking devices (Lupton, 2017). App users can store, synthesise, visualise and share their health information, and people commonly use apps to self-manage chronic illness and general health (Lupton, 2017). Market research indicates that health and medical apps were downloaded 3.7 billion times in 2017 globally (Research 2 Guidance, 2017).

Recently, there has been increasing interest in developing ‘Femtech’, a label used to describe products that aim to improve health and wellbeing for women (Kressbach, 2019). Femtech apps typically tend to focus on reproduction-related experiences like menstruation, menopause, fertility, pregnancy and parenting (Kleinman, 2019; Lupton & Maslen, 2019). Some health professionals and industry commentators frame the rise of Femtech as an overdue response to the previously androcentric digital health products developed by male-dominated technology and health industries (Fitzpatrick & Thakor, 2019; Evans, 2019). For example, the start-up NextGen Jane (which is hoping to use menstrual blood collected from a consumer’s tampon to detect early biomarkers of endometriosis) was established to help women “take true health ownership” and reduce the control doctors have over receiving an endometriosis diagnosis via laparoscopy (NextGen Jane, n.d.). There is also increased academic interest in the potential for women’s health apps to improve health outcomes for women with limited access to affordable healthcare, such as for pregnant women living rurally (Vélez, Okyere, Kanter & Bakken, 2014) or on low incomes (Bush et al., 2017).

A small body of research conducted with women suggests that these apps have been received well. Survey and interview studies have found that people enjoy using menstrual tracking apps for increasing awareness of their body’s patterns, preparing for cyclical bodily changes, conceiving or avoiding pregnancy, and informing conversations with healthcare

professionals (Epstein et al., 2017; Gambier-Ross, McLernon, & Morgan, 2018). Lupton and Maslen (2019) interviewed Australian women about how they used digital health technologies, finding that women felt health and fitness self-tracking apps afforded them more knowledge (and therefore control) of their bodies. Research on women's experiences of using apps to self-manage chronic illnesses such as hypertension and gestational diabetes reported that women see positive possibilities for medication adherence and monitoring of body data, but also concerns about monitoring increasing health anxiety (Morrissey et al., 2018) and receiving advice from apps that conflicts with medical advice (Skar et al., 2018). These studies suggest that some women increasingly experience and change their health behaviours and beliefs using self-tracking and other apps, which can have implications for how they experience embodiment (having a body) and their sense of self (Lupton, 2015). Some scholars have also theorised that technological self-management can decentre medical knowledge and increase people's agency over their bodies and health (Pettrakaki, Hilberg & Waring, 2018; Lupton & Maslen, 2019).

2.3 Social and cultural implications of women's health apps

Apps are not politically or culturally neutral; they are sociocultural objects that produce and reproduce social norms and discourses about health and illness (Bivens & Hasinoff, 2018). Compared to previous types of self-management advice, apps are more accessible (due to increased mobile internet access) and engaging (due to their interactive functionalities), making them worthy of further investigation. Empirical and theoretical research has raised concerns that health self-management apps encourage users to adhere to neoliberal ideals of citizenship. Such critiques are often heavily influenced by theorists like Foucault (1990; 2006) and Rose (1999), who argued that contemporary neoliberal governance operates through 'technologies of responsabilisation' to shift the collective burden of social problems onto individuals. In this view, health is increasingly understood as a risk

that individuals are morally responsible for managing, a trend that Crawford (1980) termed 'healthism'. For example, a focus group comprised of English adolescent girls strongly valued taking responsibility for their health by using fitness self-tracking apps (Depper & Howe, 2017). Lupton (2019) noted that app users drew on neoliberal discourses constructing the body as flawed, chaotic and in need of constant discipline, and that people using apps to manage chronic illnesses often felt burdened by the moral injunction to self-manage. Some scholars and commentators have also questioned whether women's health apps are actually designed to conduct mass surveillance of women by collecting enormous and commercially valuable datasets about their health goals and behaviours (Kressbach, 2019; Lu, 2019).

The other major criticism levelled at women's health apps is that they reinforce traditional notions about women, their bodies and appropriate performances of femininity. This research has primarily analysed apps themselves rather than users' experiences of them. For example, Kressbach (2019) highlighted the ways that menstrual tracking and fertility apps use euphemistic humour, imagery and animations to conceal the bodily experience of menstruation, reinforcing cultural beliefs that menstruation is abject. Lupton (2015) and Thomas and Lupton (2016) argued that apps for self-monitoring sexual and reproductive activities reproduced traditional ideas that women's chaotic and disorderly bodies can be controlled through medicalised surveillance and discipline. Johnson (2014) used critical discourse analysis (CDA) to examine how images and language in pregnancy apps positioned women as 'good' mothers responsible for undertaking self-surveillance to maintain the health of their foetus alongside their own. Thomas, Lupton and Pedersen (2018) also used CDA to examine how pregnancy apps reproduced a type of gendered, heteronormative parenting where expectant fathers were less interested, relevant and knowledgeable about pregnancy and parenting than expectant mothers. These studies examined how apps constructed 'healthy' women; studies have not focused on constructions of women with chronic illnesses.

Finally, researchers have also examined how contemporary self-management discourses (in women's health apps and generally) reflect an intersection of neoliberal, healthist and gendered norms. Such arguments tend to draw on the concept of 'postfeminist' femininity, which describes how women living in Western countries have been increasingly encouraged to perform femininity in ways that appear to be feminist but closely align with the needs of late capitalist neoliberal economies (Gill, 2007; Riley et al., 2019). Women's health apps often reflect postfeminist beliefs that women's bodies and minds are both inherently flawed but can (and should) be improved by constant attention, discipline and consumption; behaviours that are often framed as 'empowering' women (Riley et al., 2019). For example, Doshi (2018) argued that women's health app icons and descriptions represented 'healthy women' only in ways that aligned with traditional Western feminine ideals (i.e. thinness, Whiteness, youth, fertility, and calmness) and neoliberal performances of femininity (i.e. sexual, wealthy, empowered, independent and self-reliant).

In summary, a woman with endometriosis using an app to manage her endometriosis is part of a broader trend of women using apps to self-manage their health. Some researchers and theorists see this as a shift towards incorporating women's experiences more fully into their healthcare, while others argue that apps also reproduce dominant, hegemonic ideas about health and the role of the female citizen. Moreover, existing research predominantly focuses on how apps imagine 'health' and the 'healthy subject', but more research is needed to understand how apps construct illness and 'unhealthy' subjects, particularly for conditions like endometriosis that are heavily shaped by contested and gendered knowledge.

2.4 The current study: aims, theoretical framework and research questions

There are a small number of endometriosis-focused apps available for download and use, offering functionalities including self-tracking of endometriosis-related symptoms,

education and advice about management and treatment, and social networking platforms for people to share their experiences (Gkrozou & Waters, 2019). Gkrozou and Waters (2019) conducted a limited academic analysis focusing on whether endometriosis apps reported incorporating medical evidence into the app. Otherwise, the existing literature examining endometriosis self-management has not yet examined the emerging role of apps, including how they may reinforce or resist dominant sociocultural ideas about endometriosis.

My research aims to contribute to this gap by analysing endometriosis apps as media objects that reproduce socio-political beliefs and ideologies underpinning health and illness knowledge (Lyons, 2000). Specifically, my research aims to explore the meanings, symbols and metaphors present in app language and other forms of visual communication (i.e. images and colours) about endometriosis and people with endometriosis. My research also aims to consider potential implications of these constructions for app users. The following section outlines the feminist, critical realist theoretical framework I used to guide my analysis.

2.4.1 Theoretical framework for analysing endometriosis apps.

Social constructionism and critical realism. My research broadly fits within a social constructionist theoretical framework, which considers human experience of the world and self to be constructed through social processes, often referred to as discourses (Burr, 2015; Cromby & Nightingale, 1999). Fairclough (2010) defined discourse as the language and symbols we use to represent the world to ourselves and others. Social constructionist scholars contend that different discourses construct objects and people differently, and that multiple discourses can circulate within a society to position certain ideologies and power relations as natural (Parker, 2015). Discursive practices make available certain ‘subject positions’ that people can use to understand themselves and others (Davies & Harrè, 1990; 1999). People can accept or reject a subject position or array of subject positions; once accepted, people see

and experience the world from that position and act in accordance with the behaviours that the subject position enables or constrains (Davies & Harrè, 1999). Psychological research using a social constructionist framework and concepts can challenge the assumptions underpinning mainstream psychology (and science) that researchers can reveal the reality of the world through careful observation and experimentation (Burr, 2015). Therefore, taking a social constructionist orientation is useful for examining how a biological phenomenon like endometriosis is socially constructed.

Endometriosis impacts people's material bodies, so it is also essential that I adequately consider how the material body is constructed within, and shapes, endometriosis knowledge in the apps. Psychologists and social scientists have challenged social constructionist work that overemphasises the role of language in shaping discourse and subjective experience, arguing that it ignores 'extra-discursive' or material properties of the world (Cromby & Nightingale, 1999; Niland & Lyons, 2011). For example, critics argue that social constructionist work often prioritises symbolic constructions of the body over understanding the role of biological bodily processes on these constructions, which can dismiss people's lived, embodied experiences (Ussher, 1997). Critical realism emerged as an alternative to fully relativist forms of social constructionism; it acknowledges that language constructs our social realities but considers these constructions constrained by the material world (Parker, 2015). Critical realism enables researchers to use a material-discursive approach that integrates both material and discursive explanations (Ussher, 1997; 2011). Therefore, this was the framework employed in the present research.

Feminism. Social constructionist and critical realist researchers often draw upon feminist theory to challenge realist perspectives in psychology and medicine about women and their bodies (Ussher & Perz, 2015). For example, feminist scholars have long argued that social constructions of what a 'woman' is serve to position women as objects and men as

subjects in biomedical and psychiatric contexts (Ussher, 1997; 2011). Feminist psychologists have used critical realist, material-discursive approaches to study sexuality, reproduction and physical and mental health problems (Yardley, 1997; Ussher, 1997). Feminist work often uses material-discursive approaches as they offer a framework for acknowledging how material, bodily phenomena affect women's lived experience while acknowledging that materiality is also given social meaning through discourse. One of many relevant examples is premenstrual syndrome (PMS): Swann (1997) and Ussher and Perz (2013) argued that any theory about PMS must account for material experiences of premenstrual change alongside analyses of PMS as a Western social construct positioning the female reproductive body and menstruation as abject.

2.4.2 Research questions.

In summary, this research used a feminist, critical realist theoretical framework to explore how apps constructed endometriosis and people with endometriosis, and any potential implications of these constructions for app users. My research is based on the assumptions that a) language and other forms of visual communication techniques create powerful discourses about endometriosis and b) that these socially produced discourses offer an array of subject positions that affect the way people perceive, understand and potentially subjectively experience endometriosis. This feminist, critical realist approach enabled me to analyse how social discourses might contribute to the production of bodily experience (Swann, 1997), while considering how the material experience of having endometriosis might shape or constrain the subject positions made available (Sims-Schouten, Riley & Willig, 2007). Through a detailed analysis of both linguistic and visual features of endometriosis apps, I sought to answer the following research questions:

- How is endometriosis discursively constructed in the linguistic and non-linguistic content of endometriosis apps?
- How does the linguistic and non-linguistic content of mobile apps construct people with endometriosis (subjects), and how do they position these subjects within dominant discourses?
- What are the implications of these constructions for users of these apps?

3 Method

In this chapter, I outline my rationale for using multimodal critical discourse analysis (MCDA) as the analytical approach. I discuss how I managed the ethical issues relevant to this project, including how my subjectivity as a researcher and person with endometriosis may have influenced my analysis and research findings. Following this, I describe the procedure I used and descriptively review the five apps included in my final sample.

3.1 Analytical approach

My research examines how apps about endometriosis construct endometriosis and people with endometriosis. Apps are a relatively new and popular cultural media object that communicate ideas in highly visual and interactive ways. As with other media objects, they discursively shape actions and offer users potential subject positions drawing on ideologies (Machin & Mayr, 2012). Therefore, I used MCDA to critically analyse the visual and linguistic features of the apps.

3.1.1 Multimodal critical discourse analysis (MCDA).

Multimodal approaches to studying media texts emerged in the late 1980s and 1990s when critical linguists began considering how visual forms of communication contributed to constructing discourses alongside written and spoken language. MCDA developed out of the social semiotic branch of multimodal research, which seeks to understand how social meaning is communicated using different semiotic resources (i.e. language, gesture, image and music; Halliday, 1978; Kress & van Leeuwen, 2006). This approach analyses how discourses at the macro-political and social level constrain which semiotic resources can be used by communicators (Jewitt, 2009). This view acknowledges that images are as culturally produced as verbal language and produce subject positions and hierarchies depending on who is portrayed in what way, and who is doing the viewing (Haraway, 1991; Rose, 2007).

This approach to multimodality fits well with critical discourse analysis (CDA), a set of approaches used in the social sciences that critically examine how discourses about practices, ideas, events and identities both shape and are shaped by society (Wodak & Meyer, 2016). CDA is inherently critical; it explicitly aims to identify the power structures and ideologies transmitted through discourses and consider the consequences of such discourses on people (Fairclough, 1995). Roderick (2018) called critical discourse studies a ‘political project’ that has aimed to expose and change the way that discourses often work to hide social inequalities. To contribute to this goal, Kress and van Leeuwen (2006) developed a methodological toolkit for critically analysing how images transmit power discursively. They used the concept of ‘visual grammar’ to identify common visual elements and rules used in Western cultures that communicate messages when used together in particular ways, with a focus on what is also being obfuscated (Kress & van Leeuwen, 2006).

Visual methods are gaining momentum in psychology, as psychologists recognise that visual communication through media is an integral part of shaping people’s subjective experiences (Gibson, Lee & Crabb, 2015). Reavey (2011) noted that qualitative researchers in psychology have not traditionally paid enough attention to understanding the impact of non-verbal communication occurring in different spaces and objects. A small but growing body of psychological research has started to address this gap by examining how the visual content of media objects like magazines, websites and television shows can influence our views and shape how we think, feel and act (Lyons, 2000; Favaro, Gill & Harvey, 2017). Some of this research has employed MCDA: critical health psychologists Gibson and colleagues (2015) used MCDA to analyse how breast cancer websites constructed the idea that people with breast cancer can live well in ways that positioned women as empowered health consumers. Lindsay and Lyons (2017) used MCDA to examine constructions of masculinity and femininity in popular music videos and argued that the videos created

possible subject positions of men as playboys and women as objects. Gleeson (2011) used her own method called polytextual thematic analysis (similar to MCDA) to explore how images constructed the personhood of people with disabilities.

As with all methodologies, there are limitations to using MCDA. A major critique is that images do not have singular meanings and are always interpreted based on people's individual knowledge and experiences (Forceville, 1999). Gleeson (2011) noted that analysing visual content uses a wide range of other people's work to justify interpretations, which raises questions about the validity of findings. However, these issues are present when analysing both textual and visual data, and can be minimised by using a transparent, systematic and reflexive research process that helps readers see how analytical conclusions were reached (Braun, Clarke & Gray, 2017). Additionally, the tools used in MCDA were developed within a Western cultural context, so the meanings of visual semiotic choices may not be applicable to other cultural contexts (Kress & van Leeuwen, 2006). One of the apps in my sample (Endo Diary) was developed by a Singaporean company targeting people based in Singapore. Kress and van Leeuwen (2006) noted that Western elements co-exist with locally specific elements in Asian countries, but that their visual grammar was not explicitly developed by studying non-Western visual culture. I can still use MCDA to draw out the discourses present in Endo Diary although my interpretation is bound by my cultural position. All other apps were developed in New Zealand and the US.

3.2 Research considerations

3.2.1 Considering reflexivity.

Work grounded in a social constructionist or critical realist epistemology acknowledges that the researcher's subjective experience shapes every aspect of the research process, including how phenomena are interpreted (Willig, 2013). Braun and colleagues

(2017) noted that personal factors can provide useful insight, but also limit what we are able to see. Although every aspect of who I am will have shaped my choice of research topic, how I approached conducting the research, and the insights I developed, I identified the following aspects as particularly relevant to this project.

First, I approach this research as a cisgender woman with an endometriosis diagnosis. I recognised my own experiences in women's accounts described in the endometriosis literature. I had my symptoms minimised for eight years, was once told they were psychological, and a male gynaecologist prioritised preserving my fertility over my preference for minimising pain. I quickly learned that medical understandings of endometriosis and people with endometriosis were shaped by more than simple, objective biological 'fact'. These experiences contributed to my subsequent interest in feminist thought and activism, which guided my choice to conduct research about an issue primarily affecting women. Therefore, my commitment to improving knowledge and treatment of endometriosis is both personal and political and will have shaped my interpretations of meanings in apps.

Second, I have a particularly privileged and positive relationship with the concept of 'health' and 'healthcare'. I experience the world from a place of privilege: I am a Pākehā, middle-class woman in a long-term heterosexual relationship living in New Zealand. As such, my experience of accessing healthcare (for endometriosis and otherwise) has never been characterised overt or structural discrimination on the basis of my ethnicity, class, or sexual orientation, as is often the experience for people occupying one or more of these marginalised identities (Ministry of Health, 2019). I have felt confident engaging with healthcare professionals assertively to get my needs met and have never been unable to access medical treatment due to financial circumstances. I have studied physical and mental health issues and have worked primarily in healthcare settings. I value my health highly, and often spend considerable effort and resources in pursuit of maintaining or improving my 'health'.

Therefore, I remained aware that my interpretation of how apps construct health may differ from someone with a different relationship to health and healthcare; as Lupton (2016) noted, cultural beliefs about health and illness deeply shape responses to digital health technologies.

I attempted to remain conscious of how my subjectivity shapes my research by ‘doing reflexivity’ throughout the entire project, rather than just while writing this section (Gough, 2003). I noted how app content made me feel and recorded this during all stages of the MCDA process. I discussed and interrogated my analyses with my supervisor and peer group to ensure that my analysis remained grounded in the data (Gough, 2003).

3.2.2 Ethical issues.

The primary ethical consideration for research using apps focuses on whether online texts should be considered public or private (Eynon, Fry & Schroeder, 2017). Except for Phendo, apps were public commercial products, so I did not seek informed consent from app owners to use the content. As Phendo is the data collection interface for an active research project run by the Department of Biomedical Informatics at Columbia University, I sought and received permission from the lead researcher (Noemie Elhadad) to access the app as a researcher. I also emailed all app owners to request permission to reproduce app screenshots and emails in my thesis and received written email permission from all app owners. To access the apps, I downloaded all five apps and established researcher accounts for Flutter, MyFLO and Phendo, which required registration prior to accessing the app.

Light, Burgess and Duguay (2018) noted that researching apps with social network components can pose ethical challenges even if researchers do not generate social content themselves. They noted that users may experience disturbance if they attempt to interact with the research account, and that researchers are able to view and record a large volume of users’ personal information while accessing the app. This was not a significant problem for

this project. Flutter was the only app with an in-built social network function between users; the four other apps did not enable me to publish information within the app available for other users to see. Any social networks advertised by other apps used external platforms like Facebook. I did not access, engage with or collect information from any of these features so there is no digital trace of my account for other users to see or attempt to interact with.

3.3 Procedure

3.3.1 Data collection.

I collected the sample of apps over a two-week period in June 2019, using a systematic process to ensure all apps available to a person seeking to download an endometriosis app were included. Guided by my research question, I included all apps that explicitly focused on endometriosis and people with endometriosis. To identify relevant apps, I searched two major app marketplaces, Apple App Store (using an iPhone 6) and Google Play (using a Samsung Galaxy Tab A) using key words ‘endometriosis’ and ‘endo’. These two stores provide over 90 percent of the apps installed on smartphones (Seneviratne et al., 2015), making it appropriate to limit my search to these platforms.

This search process returned 19 results in Apple Store and a continuous stream of results in the Google Play Store with decreasing relevance to endometriosis, so I considered the first 30 results. This resulted in 41 apps in total, as eight apps were available in both marketplaces. I excluded 21 apps from the Google Play results that did not mention endometriosis in the app description, as Google’s search algorithm returned apps focused on broader issues such as recording and managing pain, tracking menstrual cycles for general use and planning fertility. I excluded five apps written in a language other than English, and five apps targeting an overly specific type of user i.e. apps for medical conference attendees, art exhibition attendees, and people with specific professional memberships.

3.3.2 Feature analysis.

I conducted a basic feature analysis of the remaining ten apps to identify those with enough visual and linguistic content to answer my research questions (Hookway, 2017). Using MCDA as an analytical approach offers rich analytic possibilities from small volumes of data, making it important that the sample size was relevant and manageable. The following major features were identified: symptom tracking, data graphing and/or export, education about endometriosis symptoms and treatment, self-management advice (e.g. nutrition, exercise), a self-diagnosis ‘tool’, journal, social network, the opportunity to participate in research, examples of other people with endometriosis, and a game/challenge component. Five apps with three or fewer functions were excluded, including two basic symptom trackers, a simple diet guide, an unfinished app, and an online support group. The final sample included five apps: Endo Diary, Endo Empowered, Flutter, MyFLO, and Phendo. I describe these apps in section 3.4 and a list of excluded apps is included at Appendix A.

3.3.3 Generating a dataset.

I generated the dataset by accessing each app and systematically taking screenshots of each page or instruction I accessed as I navigated the app (Light et al., 2018). I used the screen recording function of my data collection devices to record videos that were embedded within the app and transcribed the content of these videos. Some app features offered users the opportunity to receive images to their email addresses, which I included in the dataset. Several apps included hyperlinks to external content, such as website and blog content, Facebook pages, and YouTube videos. As this optional external content would shape how a user experienced the app, I reviewed and took descriptive notes about them but did not include them in the primary dataset. Some apps sent emails to my email address during the period of data collection. These emails were sent on an opt-out basis (rather than the opt-in

basis of choosing to click on hyperlinks) and shaped how users would experience the app, so I collected and analysed emails received during the data collection period. I did not collect or analyse content relating to individual app users, whether published by the app (e.g. testimonials) or by the user, or content relating to app settings or administration.

All data points (screenshot, email or video recording) were coded, numbered and the full dataset was printed for analysis. The full dataset comprised of 385 screenshots (equivalent to 251 individual app screens; some screenshots captured scrolling through content or multiple tracking options on the same screen), three videos and 18 emails. Electronic copies were kept in secure university cloud-based storage services.

3.3.4 Analysis.

Familiarisation. The data collection process generated a large volume of data, which varied in terms of its relevance for understanding constructions of endometriosis and people with endometriosis. Therefore, I first familiarised myself with the data by repeatedly reading and visually assessing the screenshots, emails and videos while taking detailed descriptive notes (Braun & Clarke, 2013). I considered each individual data point's content, layout, and use of colour and/or images, and looked for similarities and differences across the apps (Gibson et al., 2015). I also recorded how the data made me feel, as researcher feelings can offer valuable analytic insights and identify how my subjectivity may have shaped and constrained how I interpreted the data (Braun & Clarke, 2013).

Identifying initial discursive themes. The second stage of analysis involved generating themes from my data by coding examples of data that related to endometriosis or people with endometriosis. I drew on aspects of Braun and Clarke's (2013) guidelines for conducting thematic analysis, which recommended that novice researchers combine complete and selective coding approaches. This process involved broadly coding potentially interesting

features in the dataset to identify a) features that stood out as meaningful and b) features that recurred across each of the apps. I identified 81 codes across several areas, which I grouped by categories like aesthetic choices (e.g. font, colour, images), app navigation, functionality (e.g. self-tracking, data visualisation) information about endometriosis (e.g. definitions of endometriosis) recommended interventions (e.g. surgery, diet changes) and broader general themes (see full list at Appendix B). Then, I selectively coded specific examples of each feature in the dataset and grouped them into themes. This process involved identifying themes in the way that apps used text, images, colour, and layout choices, searching for ‘recurring and linked patterns of meaning’ and beginning to interpret them (Gleeson, 2011).

MCDA. The third stage of my research was conducting a deep multimodal analysis of the visual and linguistic features in each app to identify the discourses present in the apps. I combined three approaches to guide this process. I used guidelines from Ussher and Perz (2015) to undertake the CDA, which I supplemented with advice and guidelines about MCDA published Kress and van Leeuwen (2006) and Machin and Mayr (2012). I used the evidence and theory offered by these texts to closely examine how apps used visual and linguistic strategies (e.g. symbols, metaphors, similes) to construct various phenomena, people and power relations. For example, I examined how images constructed people by using gaze, pose, distance, setting, abstract symbolism, and activities (Machin & Mayr, 2012). As part of identifying discourses, I searched for potential subject positions offered to app users and questioned what possible ideological goals or functions these might serve. As qualitative research is recursive, I often revised my interpretation of constructions, discourses and subject positions throughout the writing process.

3.4 Description of apps

As a researcher, the first engagement with each app occurred during the process of identifying the sample. Table 1 displays key details about each of the five apps included in the final sample, while Figure 1 shows screenshots of each app, as presented in the Apple App Store when viewed from an Apple iPhone 5S. Initial information provided in this screen included the app name, category or app subtitle, star rating (if available) and three screenshots of different screens in the app. Appendix C provides more detailed information about what each of the three advertising panels displayed in each screenshot.

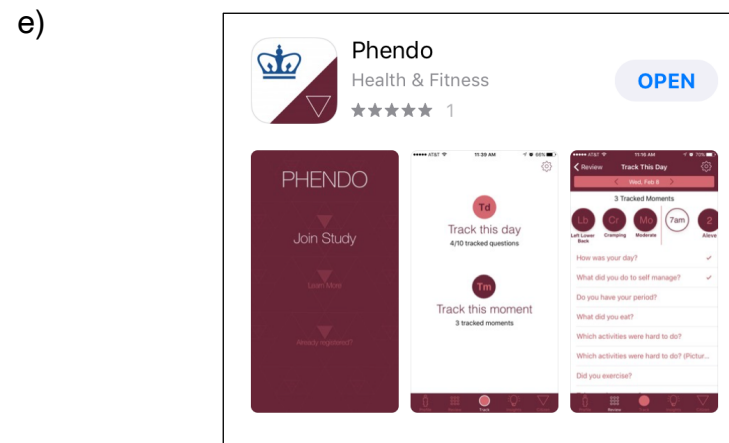
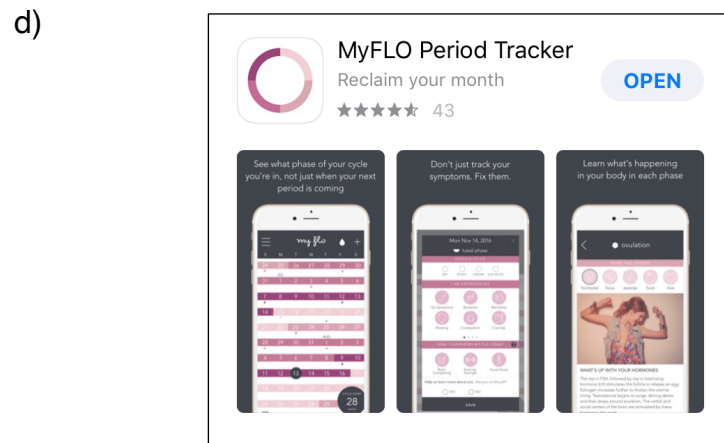
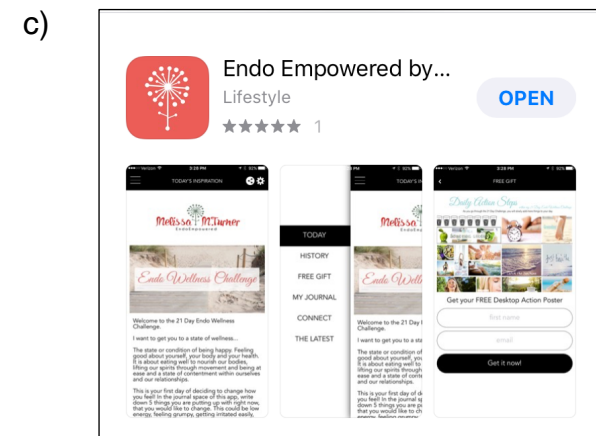
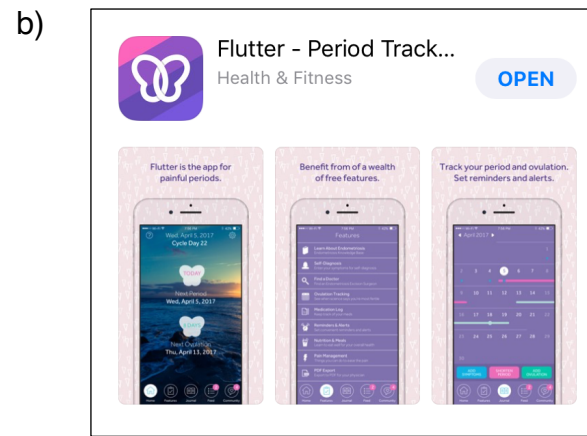
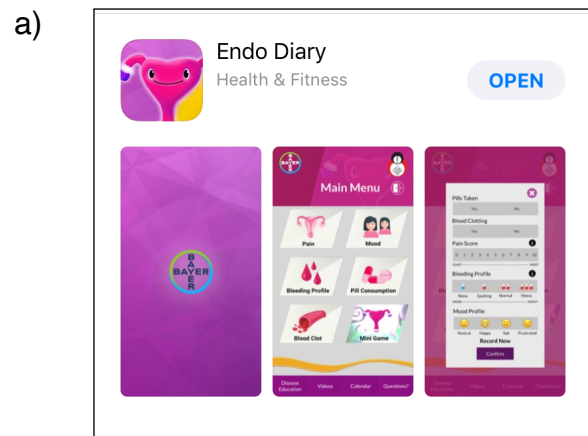


Figure 1. Screenshots of each of the five apps in the sample as presented in the Apple App Store when viewed from an Apple iPhone 5S. Each screenshot shows the app name, category or app subtitle, star rating (if available) and three screenshots of different screens in the app.

CONTROLLING THE MONSTER: ENDOMETRIOSIS APPS

Table 1

Basic details of endometriosis apps in sample

App name	Price	Availability in app stores		Category	App developer/owner
		Apple Store	Google Store		
Endo Diary	Free	Yes	Yes	Health & Fitness	Bayer Group
Endo Empowered	Free	Yes	No	Lifestyle	Melissa Turner
Flutter	Free	Yes	No	Health & Fitness	Flutter Health Inc.
MyFLO	\$3.49	Yes	Yes	Health & Fitness	Flo Living LLC
Phendo	Free	Yes	Yes	Health & Fitness (Apple); Medical (Google)	Noemie Elhadad

Endo Diary was developed by the Singapore branch of Bayer Group, a large multinational pharmaceutical company. The logo for the Obstetrical and Gynaecological Society Singapore (OGSS) appears on the ‘Main Menu’ screen of the app, suggesting that they were involved in its development in some capacity. Endo Diary aimed to facilitate biomedical interventions by improving patient adherence to treatment, improving medical consultation productivity by offering patient education and using “patient condition tracking to enable doctors to make informed decision and improve diagnosis” (Bayer Group, 2019). Endo Diary features included simple self-tracking and data visualisation, a ‘mini-game’, information about endometriosis, and links to websites of Singaporean medical institutions.

Endo Empowered is part of Melissa Turner’s company of the same name, which offers membership-based guidance for managing endometriosis using holistic and natural approaches. The Endo Empowered app is a free, “21 Day Endo Wellness Challenge”, where users are sent daily ‘challenges’ for 21 days that recommend different lifestyle behaviours to improve endometriosis symptoms. The app was designed to help women with endometriosis

to “support their bodies with the basics of wellness” (Turner, 2016). Endo Empowered encouraged users to record their experiences using a journal function and provided a downloadable “Daily Action Steps” poster for users to track their wellness behaviours.

Flutter described itself as “the app for painful periods”, although it specifically focused on endometriosis (Flutter Health, 2016). Flutter’s features included tracking of users’ menstruation cycles (including ovulation), daily tracking of endometriosis symptoms, quality of life, and behaviours, information about endometriosis, nutrition, and pain management, a self-diagnosis test, birth control reminders, and a message board for users to discuss various issues. Other features were broken during the study, such as a PDF export feature of tracked data, a ‘feed’ of new information, and a directory of gynaecologists with very few listings.

MyFLO is part of FLO Living, a company developed by functional nutritionist Alisa Vitti. MyFLO aimed to help women with ‘hormonal symptoms’ track their menstrual cycle and symptoms (Flo Living, 2016). MyFLO was designed for people with endometriosis as well as other conditions (e.g. polycystic ovary syndrome, uterine fibroids), but was included it because it is likely to be used by people with endometriosis. The app included a menstruation and symptom tracker, recommendations (primarily dietary) for resolving symptoms, and a “My Cycle Phases” feature offering users advice on how to eat, exercise, work, socialise and have sex depending on which stage of the menstrual cycle they were in. The app also offered links to FLO Living’s “FLO Rx [Prescriptions]”, which were dietary supplement subscriptions and private counselling sessions that users could pay for separately.

Phendo is a data collection platform for a research project called Citizen Endo, which is being run by the Department of Biomedical Informatics at Columbia University in the US. The study aims to develop phenotypes of endometriosis by cataloguing the “signs and symptoms of endometriosis”, comorbid conditions, and self-management information

reported by people who have experienced symptoms typically associated with endometriosis (Elhadad, 2016). As such, the tracking features formed the bulk of the app. Potential app users were required to provide fully informed consent before they could begin using the app.

3.4.1 Other important features: app development and data protection.

Limited app development. There was a sense of limited app development. All apps experienced at least one of the following technical problems: difficulty loading, unexpectedly shutting down, difficult navigation around app, broken functions or links, and placeholders for future feature development. App formatting and design was also simple and appeared unfinished at times.

Privacy and security. The amount of privacy and security information offered to users was typically insufficient. Endo Diary and Endo Empowered did not provide any information about how they collected, stored or used data, despite collecting (albeit basic) menstrual tracking and free-text journal data. Flutter and MyFLO set out what data would be collected and how data would be used and/or shared, although the notification used broad and overly general definitions to enable significant collection and use of personal information. For example, Flutter included phrases like “Personally identifiable information may include, but is not limited to, your email address, name, other information”. MyFLO explicitly explained that health-related data (including menstrual cycle data and free text comments) were collected and used for advertising and marketing. Both apps used third-party services such as Google Analytics but offered minimal detail about the exact nature of the data collected and how it was used; MyFLO said it was used to “optimise [their] business”. Flutter’s Privacy Policy offered users directions for opting out of some data collection.

Conversely, Phendo outlined specifically what data was collected, how it was stored, who would have access to identifiable and de-identified data respectively, and how it would

be destroyed. Other than Phendo, apps offered little information about the data security measures they used to protect user identifiable data, beyond stating that measures to protect data were reasonable and commercially acceptable.

4 Endometriosis: A Disease of the Female Reproductive Body

In this first analytic chapter, I analyse how visual and linguistic features of endometriosis apps constructed endometriosis as a disease of the female reproductive body. I use multimodal evidence to argue that this core construction drew heavily upon biological and biomedical discourses that consider female biology to be abject and out of control. These discourses, along with discourses of traditional femininity and gender essentialism, further constructed endometriosis as a threat to normative performances of femininity. This is the first of three analysis chapters; in Chapter 5, I demonstrate how apps encouraged users to self-track as a way to understand a confusing and all-encompassing endometriosis. In Chapter 6, I demonstrate how apps constructed controlling endometriosis as possible and desirable in ways that reflected dominant neoliberal, healthist and postfeminist discourses.

4.1 Constructing endometriosis as a disease of the female reproductive body

As discussed in Chapter 1, the biomedical, scientific and social scientific academic literatures trying to define, explain and theorise endometriosis are characterised by messiness, complexity and uncertainty. In contrast, apps presented a relatively simple and uniform definition and description of endometriosis. Apps with a biomedical orientation tended to call endometriosis a ‘disease’, while apps with a less biomedical orientation (what I refer to as a ‘natural’ or ‘wellness’ orientation) used phrases like ‘condition’, ‘challenge’ or ‘problem’. Despite these minor wording variations, apps used similar discursive strategies to construct endometriosis as a disease of the female reproductive body, including the colour pink, imagery of female biology and women, scientific imagery, and linguistic content.

4.1.1 Many shades of pink.

All apps linked endometriosis to the female sex and gender through the ubiquitous use of the colour pink in app colour schemes. As shown throughout Figures 1 to 7, apps used a

range of shades of pink, from the darker ruby and mauves of MyFLO and Phendo, the shocking cerise used heavily throughout Endo Diary, to the paler pink accents of Flutter and Endo Empowered. Apps also used red and purple to a lesser extent. Apps typically used black text presented on a white background, a formal communication style suggesting that the app's information and services are factual and serious, while the accompanying pink communicated that the content is inherently feminine and constructed endometriosis as a women's issue (van Leeuwen, 2011). Koller (2007) argued that pink is widely used across commercial and health settings to code products or topics as feminine to attract women to use and engage with them, suggesting that the ubiquitous use of pink across the apps may be an attempt to encourage women to use the app. However, pink communicates more than simply being 'about women'; it is now commonly used to communicate postfeminist values such as fun, independence and power (Koller, 2007; Lazar, 2009). Therefore, the apps' heavy use of pink (reinforced by other visual and linguistic features) may have constructed women with endometriosis who use an app as enacting this postfeminist 'empowered' femininity.

4.1.2 Imagery of female biology and women.

Apps also used overt and symbolic imagery depicting female reproductive organs, menstruation and hormones to construct endometriosis as disease of the female reproductive body. This discursive strategy first emerged during analysis of the app icons; all five icons depicted or alluded to aspects of female biology, shown in Figure 2.a to 2.e. Endo Diary's icon used the most overt imagery, depicting a cartoon, personified set of fluffy, wide-eyed and smiling female reproductive organs. Other app icons used shapes and silhouettes that resembled common anatomical depictions of the uterus, ovaries and vagina. Endo Empowered's dandelion pappus evoked the imagery of a uterus (the pappus) connected to the vagina (the stem), while the shape and soft, curved edges of Flutter's butterfly also resembled a uterus. The dandelion pappus and butterfly are commonly used in Western culture to

symbolise freedom due to their ability to ‘fly away’; in Chapter 6, I discuss how these symbols constructed managing endometriosis as a journey or ‘quest’ (Frank, 1995). Phendo’s inverted maroon triangle also resembled a uterus; in this case, being paired with the Columbia University logo communicated the academic purpose and scientific credibility of the app. The app MyFLO focused on a broader set of ‘hormonal problems’ than the other apps, so their icon used a circle representing the four stages of the menstrual cycle. From the perspective of a user opening the app for the first time, these icons immediately discursively linked endometriosis (and other related conditions, in the case of MyFLO) with the female reproductive body and processes.

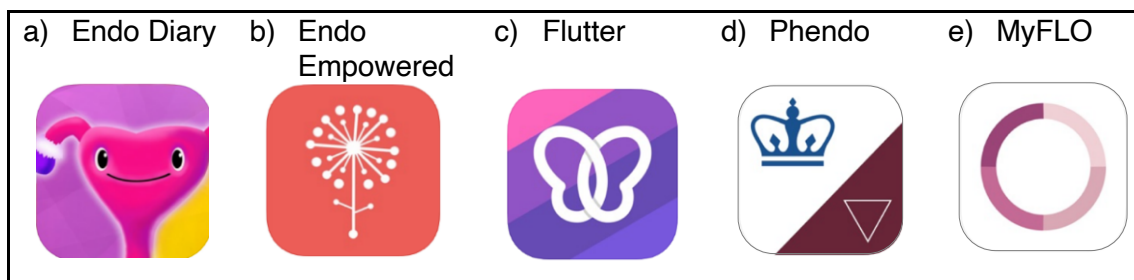


Figure 2. Cropped screenshots of app icons used to illustrate apps in the Apple and Google Play app stores and on mobile device once installed. Reproduced with permission.

As well as constructing endometriosis as a problem of female biology, apps used iconography and images to construct all people with endometriosis as women. Phendo used the outline of a person in a dress to illustrate the ‘Profile’ button, a common symbol used to signify that something relates to ‘women’. In this way, Phendo constructed users as women, despite asking users to identify their gender during the registration process. Figure 3 shows a partial screenshot from the ‘Ovulation’ section of MyFLO’s ‘My Cycle Phases’; a feature that offered users advice about ‘normal’ levels of different hormones (particularly ‘female’ sex hormones, oestrogen and progesterone) occurring in the female body throughout the four stages of the menstrual cycle. In addition to MyFLO’s characteristic light pink accents, MyFLO discursively produced specific patterns and levels of hormones as female by using

the symbol ♀ for woman to accompany the ‘Hormones’ information. The title ‘Ovulation’ was accompanied by a whole of a white circle on a dark grey background; other phases were also accompanied by the quarter or half circles commonly used to represent phases of the moon. Therefore, this pairing may have reflected the widespread cultural association of femininity with nature to discursively produce ‘normal’ menstruation cycles as synchronous with the natural lunar cycle (Tan, Haththotuwa & Fraser, 2017).

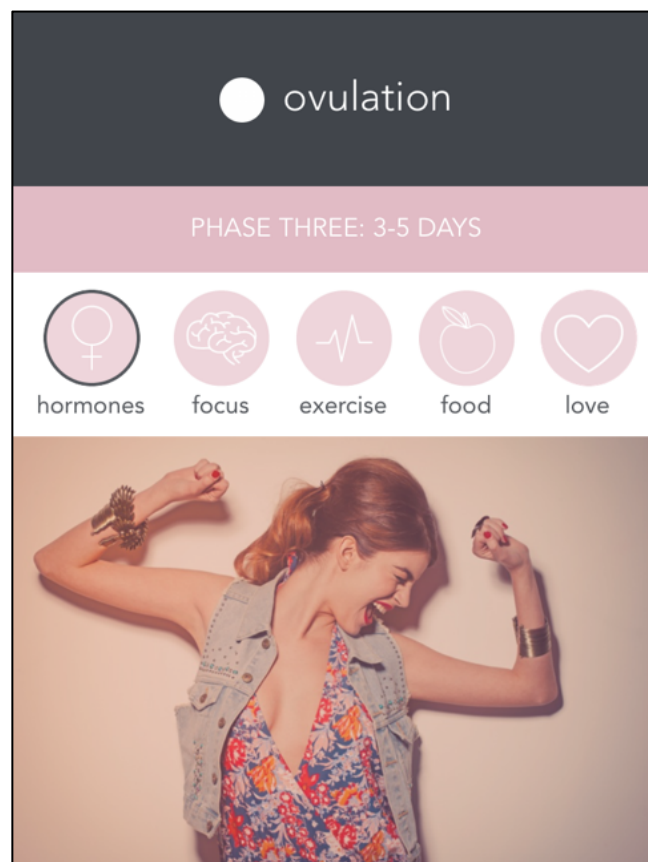


Figure 3. A partial screenshot from the ‘Hormones’ screen of the ‘Ovulation’ section of the ‘My Cycle Phases’ section of MyFLO. A text section below image [not shown] titled “What’s up with my hormones?” provided information about ideal hormone levels during ovulation and advice about ideal user behaviour to optimise hormones. Images linked to information about ‘focus’, ‘exercise’, ‘food’ and ‘love’. Reproduced with permission.

App images and content also communicated that ‘female’ hormones meaningfully shape what it means to be a ‘woman’, reflecting the dominant discourse that women’s

essences are defined by their biological bodies (Grosz, 1994; Roberts, 2007). MyFLO discursively linked female biology with femininity by accompanying information about healthy female hormones with an image of a highly feminine woman raising her hands and cheering in a way that connoted postfeminist ideals of power, happiness and enthusiasm (Riley et al., 2019). The image constructed having ‘normal’ levels of female hormones as a powerful force enabling women to be powerful, happy and enthusiastic. By focusing on how ‘normal’, ‘natural’ and ‘balanced’ hormonal patterns positively shape women’s lives, MyFLO constructed endometriosis (and other problems) as the opposite - a result of abnormal, unnatural and imbalanced hormones.

The woman in Figure 3 demonstrates how apps typically imagined women in ways that aligned with dominant discourses about femininity and health. Apps depicted women as highly feminine (e.g. styled hair, make-up, clothes and painted nails), young, clear-skinned, thin, able-bodied and happy. Additionally, the women depicted were nearly always White, although Endo Diary and MyFLO included occasional depictions of light-skinned women from non-White ethnicities. Such narrow representations of women reflected gendered and healthist discourses that construct the healthy female subject as young, fit, thin, physically attractive and usually White (Doshi, 2018). Such images may reflect that app users tend to be younger, healthier and have higher incomes relative to the general population (Carroll et al., 2017) but could also reflect historic biomedical constructions of endometriosis as predominantly affecting white, middle- and upper-class women (Nezhat et al., 2012). Thus, apps constructed endometriosis as a disease or abnormality of the female reproductive body at the same time as they constructed women with normal biology in ways that aligned with dominant and idealised versions of healthy femininity. Together, these related constructions communicated that endometriosis threatens a user’s ability to take up the subject position of a feminine, healthy woman. Instead, users with endometriosis were offered an abject subject

position drawing on social discourses that conflate failed female biology with failed femininity (discussed further in section 4.3).

4.1.3 Scientific imagery.

Apps with a biomedical orientation further emphasised that endometriosis was a disease by using design features and scientific and technological images common within biomedicine. Biomedically oriented apps universally used ‘sensible’ sans serif fonts in their logos and front pages in contrast to the elaborate cursive preferred by apps with a wellness or natural orientation (see Figure 1 for examples). Furthermore, Figure 4 shows a slide from a PowerPoint presentation published by Endo Diary. The slide focused on how endometriosis diagnoses are made and featured overtly biomedical images of female reproductive organs: a diagram of a gloved hand performing a clinical vaginal examination upon a cross-sectioned female body, next to images of endometriosis captured with laparoscopic and magnetic resonance imaging.



Figure 4. Screenshot of slide titled 'How are diagnoses made?' from “Endo Diary PowerPoint Slides”, in the 'Disease Education' section of Endo Diary. Reproduced with permission.

These scientific images served two related discursive functions. First, scientific diagrams and biotechnological imaging are typically considered to be objective depictions of reality (Tufte, 1997; Kress & van Leeuwen, 2006). Therefore, their inclusion in Endo Diary serves to reveal the ‘true nature’ of endometriosis as a pathology within the individual, material body. Second, these images reinforced dominant biomedical discourses by constructing endometriosis (and the female body) as objects of expert medical and biotechnological surveillance and intervention (Shohat, 1992; Ussher, 2006). The PowerPoint presentation was published within the ‘Disease Education’ section of the app, further reinforcing that endometriosis is something biomedical practitioners (including those who developed the app) have expert knowledge about and as something that the female user with endometriosis needs to be educated about. The existence of the ‘Disease Education’ section, supported by the images and content, positioned apps as pedagogical agents and users as learners that lack knowledge about endometriosis.

Other apps used scientific imagery and symbols to discursively construct endometriosis as a disease. In contrast to Endo Diary, Phendo used few images. As it is the data collection interface for a biomedical informatics research project aiming to understand phenotypes of endometriosis, most of the app offered self-tracking of symptoms and behaviours thought to be related to endometriosis. Most of the app’s screens used black text with mauve or pink accents on a white background; a minimalist design aesthetic which Tufte (1997) argued functions to increase inherent truth value of information by associating visual clarity with factual or conceptual clarity. Figure 5 shows a partial screenshot of a typical tracking question; app users were asked to select from a range of options to record where their pain is located, and to describe the qualitative nature and severity of that pain. Each possible option was accompanied by a mauve circle enclosing an upper- and lower-case letter, drawing on the format used in science to represent physical elements. For example,

pain felt in the left pelvis was accompanied by an ‘Lp’ symbol, while an aching type of pain was denoted by an ‘Ac’ symbol. These classic scientific symbols, muted colour palette and anatomical language situated Phendo within scientific discourses and constructed endometriosis as best understood through scientific research (Kressbach, 2019). It also positioned app users as contributing to credible, legitimate scientific research by closely recording their symptoms and behaviour.

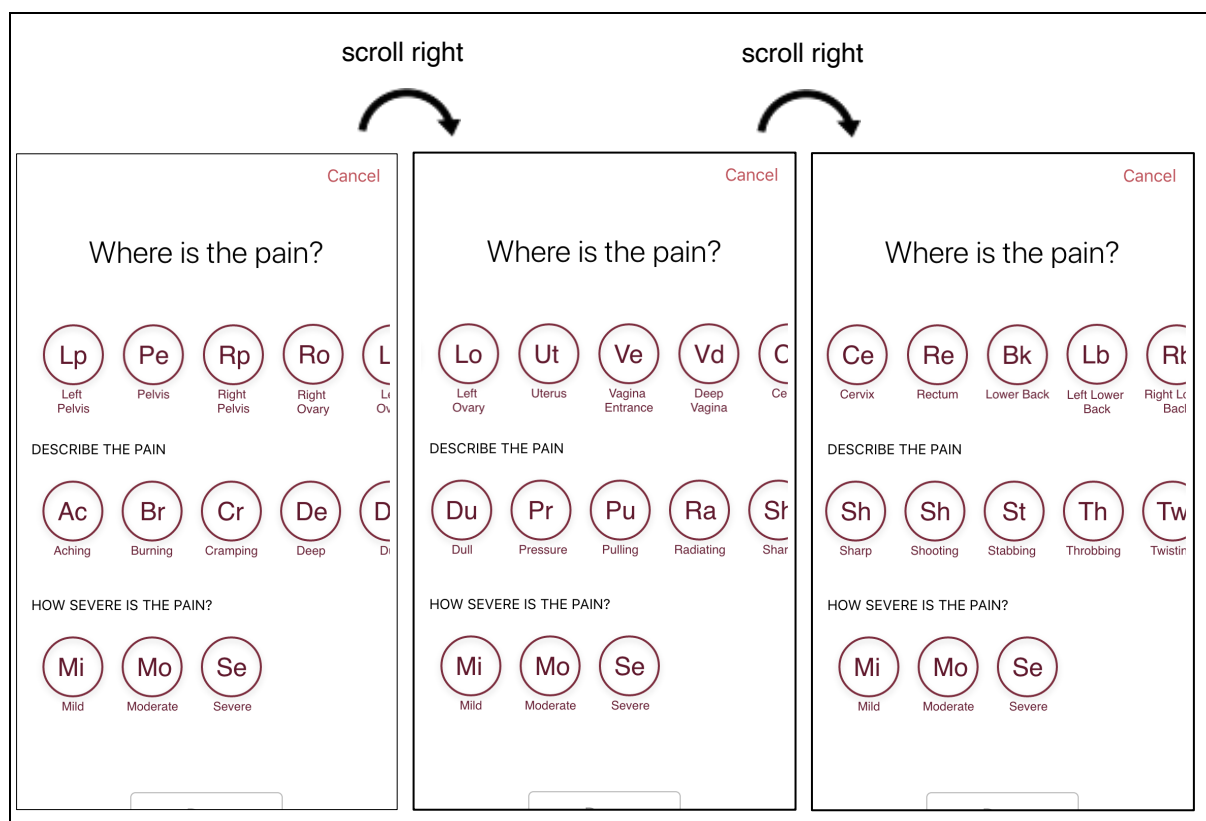


Figure 5. Three partial screenshots of the ‘Where is the pain?’ question in the ‘Track this moment’ feature of Phendo. The question allows users to select from 38 pain locations across the body, 15 pain descriptors, and three levels of severity. Users were able to scroll to the right to see all options. Reproduced with permission.

The number of available answers to the “Where is the pain?” question also demonstrates the detailed self-monitoring of pain and other bodily symptoms that the apps encouraged app users to perform. Although the screenshots shown in Figure 5 only fully

show twelve of both pain location and descriptions, users were able to choose from 38 pain locations across the body (including broad categories like ‘joints’, ‘bones’, and ‘legs’) and 15 pain descriptions. There was considerable overlap across the options, requiring users to be able to focus on and distinguish between particular internal organs – such as deciding whether to record that pain was being felt in the pelvis, ovary, uterus, deep vagina, cervix, or abdomen. The idea that tracking bodily experiences is meaningful for people with endometriosis will be discussed in Chapter 5, but the current example demonstrates how apps positioned users with endometriosis as people who regularly experience identifiable and recordable sensations or ‘symptoms’ (i.e. pain) in specific body parts. This construction of endometriosis as characterised by pain in highly localised places could encourage users to compartmentalise their bodily experiences of endometriosis and attend more to those that align with dominant constructions of endometriosis as a gynaecological issue. Furthermore, some evidence suggests that attending to pain can amplify a person’s subjective experience of pain, particularly when trying to control it (Van Damme, Legrain, Vogt & Crombez, 2010). Therefore, encouraging users to constantly attend to pain could directly increase their discomfort. Phendo appeared to acknowledge this risk during the informed consent process by saying “You may find it uncomfortable to track your experience of endometriosis” but managed this by telling users that tracking was optional.

4.1.4 Linguistic content.

Although apps generally offered few descriptions or explanations of endometriosis, apps most commonly described endometriosis symptoms that were gynaecological and menstrual, related to organs in close proximity to the uterus (i.e. digestive and urinary problems and back/leg pain) or caused by primary symptoms (i.e. fatigue, mood problems). This gynaecological focus is demonstrated by the following extract from Flutter, titled “What is endometriosis?”:

Endometriosis is a disease in which tissue (called the endometrium) which normally grows only in the uterus grows outside of it. With endometriosis the tissue can be found on the ovaries, in the fallopian tubes, in the abdomen and on the ligaments around the uterus. This unwelcome tissue receives the same hormonal trigger to bleed as does the endometrium inside the uterus. Whereas the shedding endometrium inside the uterus exits via the vagina each month (your period), the misplaced tissue bleeds into your body causing lesions and inflammation which cause adhesions, scars, infertility and painful periods, ovulation and bowel movements (Flutter, 2019).

In Flutter's definition, endometrial tissue was constructed as abnormal, unwelcome, and misplaced, drawing heavily on the dualistic separation of 'inside' and 'outside': endometrium inside the uterus is cast as good, while endometrium outside the uterus is cast as bad. This sense of endometriosis as 'matter out of place' was further demonstrated by the statement that the tissue "bleeds into your body", which discursively separated the body from the endometrium, as if the endometrium is not part of the body, but an invasive external polluter. The hormones required for typical menstruation (apps primarily focused on the role of oestrogen) were constructed as triggering bleeding of the misplaced tissue. Such wording constructed this type of menstruation and menstrual blood as abject, even though endometrium is commonly found outside of the uterus in people without endometriosis (Gupta et al., 2015). In this way, Flutter reinforced pervasive beliefs within biomedical discourse that even typical menstruation is abnormal (Shohat, 1992; Jones, 2016).

Flutter's construction of infertility (i.e. the failure to achieve a successful pregnancy) as a 'symptom' or marker of disease reflected dominant social discourses that reproduction is a normal and natural part of womanhood, potentially offering women with endometriosis who do not or cannot reproduce an abject subject position (Ussher, 2006). Compared to other apps, Flutter was the most focused on constructing reproduction as a normative part of

womanhood and endometriosis management; several features and articles focused on achieving and enjoying pregnancy. Other apps (Endo Diary and MyFLO) also briefly described infertility as a symptom of endometriosis, but otherwise did not emphasise fertility as a specific goal for women with endometriosis. Given that the apps heavily constructed other aspects of normative femininity as desirable, the relative absence of injunctions to reproduce may reflect that apps resisted drawing on biomedical discourses that endometriosis is caused by delayed childbearing (Seear, 2014).

Flutter's simple description of endometriosis as extrapelvic endometrium causing "infertility and painful periods, ovulation and bowel movements" was characteristic of the way that apps did not attend to the complexity and contradictions in the scientific and biomedical endometriosis literatures. In Chapter 5, I discuss how apps constructed endometriosis as confusing in ways that did not challenge dominant biomedical understandings of endometriosis as a gynaecological and menstrual disorder. Constructing endometriosis knowledge as simple reinforced the claims to scientific and medical credibility and authority previously discussed and positioned biomedical practitioners or other biological experts (such as naturopathic nutritionists) as knowing the 'truth' about endometriosis. In this way, women with endometriosis were positioned as patients and/or consumers who should rely on these experts to achieve a simple solution for managing their endometriosis.

Two apps did briefly acknowledge that endometriosis symptoms can extend beyond the reproductive and closely located organs. Phendo offered options to record pain and other experiences felt throughout the entire body, and Endo Diary republished an article acknowledging that endometriosis can be found "anywhere from the vulva to your brain, and everywhere in between". Notably, Endo Diary's statement referred to 'the vulva', but 'your brain', discursively separating the user's self from their vulva but not from their brain. Chrisler and Johnston-Robledo (2018) argued that a woman's desire to "separate the self

from the messy corporeality of menstruation” (p. 101) or their reproductive body more generally may reflect higher levels of self-objectification (i.e. internalising a critical gaze on their own bodies). Given that levels of negative attitudes towards menstruation and levels of self-objectification are positively associated (Johnston-Robledo, Sheffield, Voigt & Wilcox-Constantine, 2007), Endo Diary’s statement may reflect the negative attitudes towards menstruation (especially endometriosis-related menstruation) demonstrated by several apps.

Apps generally constructed difficult experiences of menstruation, and specific qualities of menstrual blood, as negative. For example, one of Endo Empowered’s daily challenges asked users “Is your period lumpy, thick and dark? Let’s dilute the situation with some water”. Endo Empowered did not explain why menstrual blood with those qualities was problematic, nor how such qualities related to endometriosis. However, the adjectives ‘lumpy’, ‘thick’ and ‘dark’ are antonyms of ‘smooth’, ‘thin’ and ‘light’, which are all positively associated with Western feminine beauty ideals (Doshi, 2018). Therefore, Endo Empowered’s construction of lumpy, thick and dark menstruation as undesirable and abject appeared to reflect cultural disgust and stigma toward menstruation and constructed endometriosis as causing a particularly unclean, unfeminine form of menstruation (Johnston-Robledo & Chrisler, 2013). Given that women commonly internalise negative constructions of menstruation as unclean and unfeminine (Chrisler & Johnston-Robledo, 2018; Ussher, 2006), constructing qualities of endometriosis-related menstruation as especially polluting and abject offered women with endometriosis a highly stigmatising and shameful subject position of being even more unclean, unfeminine and monstrous than other women.

Apps with a natural or wellness orientation also drew on biological discourses to construct endometriosis as a hormonal or biological imbalance located within the female reproductive body, even if they challenged other aspects of biomedical knowledge about endometriosis and women’s bodies. For example, Figure 6 shows a pair of screenshots

advertising MyFLO's monthly flo "prescription"; a three-month online food therapy programme (retailing at USD\$297) that "recalibrates your endocrine function" to "fix your period problems, from PCOS [polycystic ovary syndrome], to PMS [premenstrual syndrome] to [uterine] fibroids, endo, heavy bleeding, cramps and more". Listed 'period problems' included endometriosis alongside other conditions and embodied experiences (i.e. cramps) constructed as gynaecological within biomedical discourses. In this way, MyFLO produced endometriosis as simply one potential manifestation of living in "hormonal chaos", rather than a distinct disorder with its own aetiology.

MyFLO described menstrual changes as unwanted symptoms that inhibit productivity and offered users the alternative possibility of "feeling good all month long" by having "symptom-free periods". As with Endo Empowered, this discursively created 'healthy' and 'unhealthy' forms of menstruation, whereby users who experience 'symptomatic' menstruation (whether due to endometriosis or not) were offered an 'unhealthy' subject position. As will be discussed in Chapter 6, healthy menstruation was also constructed in ways that aligned with neoliberal discourses that construct self-optimisation and productivity as part of being healthy (Riley et al., 2019). MyFLO's linguistic construction of abject menstruation caused by dysfunctional hormones was visually supported by the pink-toned image of a highly feminine pair of hands loosely holding an abdomen. Kress and van Leeuwen (2006) note that images placed at the top of a text are often used to signify the 'essence' of the information, while the bottom is often used to convey details. Therefore, the 'clutching abdomen' image discursively produced hormonal dysfunction in women as inherently linked to the abdominal region and reflected dominant discourses that the female reproductive body is a source of danger and debilitation (Ussher, 2006).

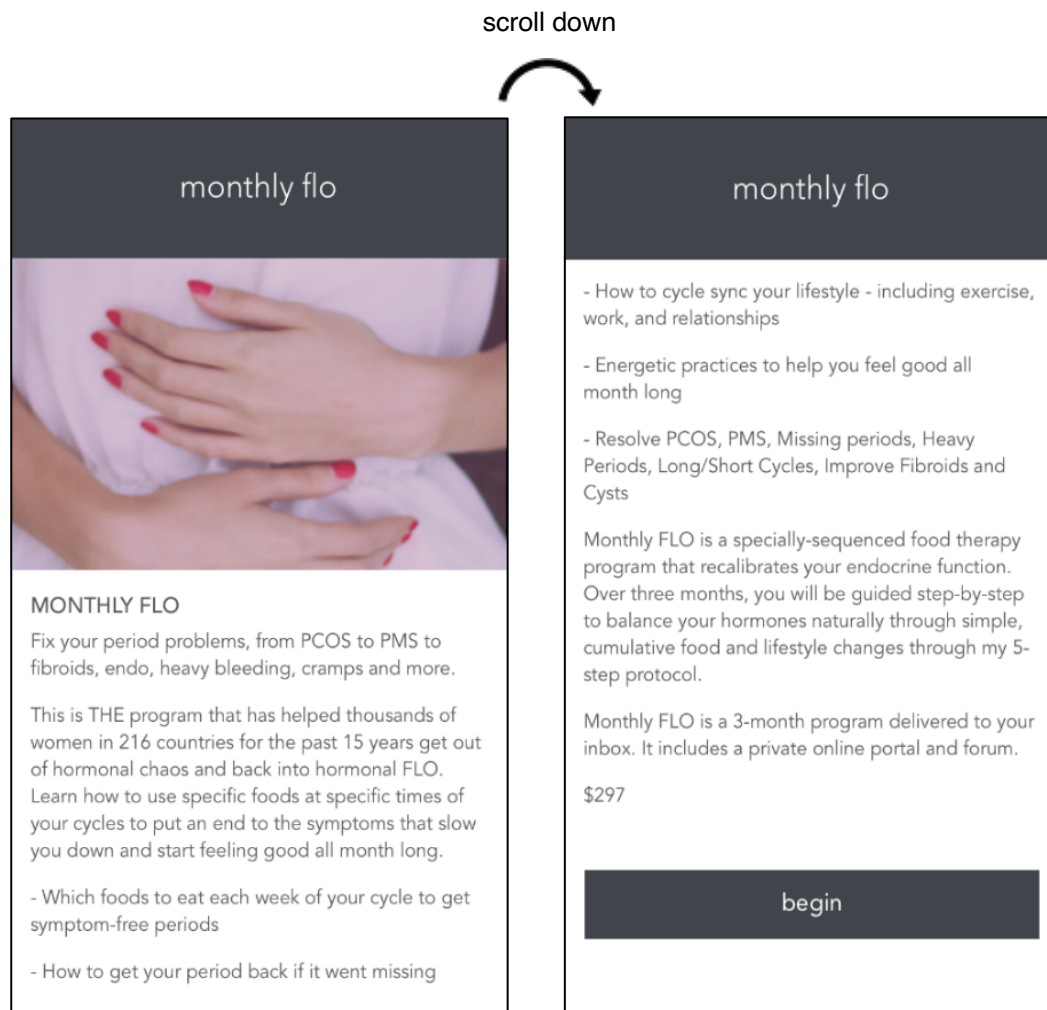


Figure 6. Two partial screenshots of the ‘monthly flo’ ‘prescription’ from the MyFLO app. Pressing the ‘begin’ button links users to the Flo Living website where they can purchase access to the programme. Reproduced with permission.

MyFLO also constructed endometriosis as a biological problem by producing it as something that can be “fixed” or cured through a dietary and behavioural recalibration of endocrine function. Endo Empowered also constructed endometriosis as curable by making regular references to “achieving wellness”, “correcting” imbalances, and “resolving” endometriosis. While the idea that endometriosis was curable was not shared by the apps drawing more heavily on biomedical discourses, all apps produced endometriosis as something occurring within the body. For example, MyFLO called the ‘monthly flo’

programme a ‘prescription’, which metaphorically produced the recommendations as ‘medicine’ prescribed by an expert to treat pathology in the body. This functioned to position women with endometriosis as sufferers of a biological disease or imbalance, and enabled apps to recommend interventions for endometriosis that focused on the individual body (discussed in Chapters 5 and 6).

4.1.5 Specific case example: Endo Diary’s main menu.

The main menu of Endo Diary shown in Figure 7 demonstrates how colour, imagery and language worked together to construct female reproductive organs, menstruation and hormones as centrally implicated in endometriosis. First, the Bayer and Obstetrical and Gynaecology Society of Singapore (OGSS) logos were located at the top of the screen, which afforded scientific and medical credibility to the app’s claims (Kress & van Leeuwen, 2006). Below this, the screen presented six white buttons, five of which offered users the ability to track a different key feature of endometriosis: Pain, Mood, Bleeding Profile, Pill Consumption, and Blood Clot. Each word was presented on the white button in plain black text underneath a pink-toned image representing each feature.

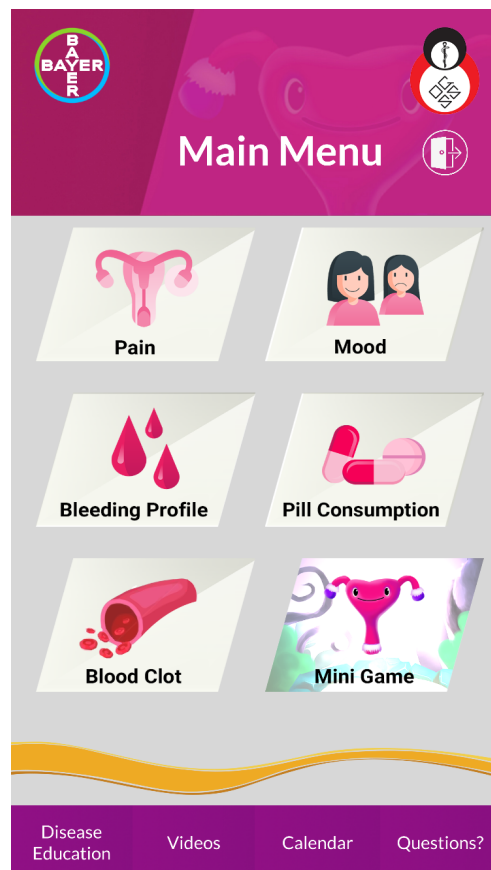


Figure 7. Screenshot of the Main Menu in the Endo Diary app. The six buttons offered five self-tracking categories and access to a basic game. Four buttons at the bottom of the screen offered information about endometriosis, a tracking summary and contact information.

Reproduced with permission.

The first trackable feature was Pain, the text accompanied by an image of a decontextualized, cartoon set of pink female internal reproductive organs: a vagina, uterus, fallopian tubes and ovaries. Kress and van Leeuwen (2006) note that when concepts are decontextualized from a specific time or place and placed on a plain background in this way, it discursively links the concepts as a generic or typical association. Therefore, Endo Diary reinforced existing biomedical discourses that endometriosis-related pain originates from and is felt within the female reproductive organs. Users were able to score their pain from 0 to 10, but could not record where pain is felt, communicating that pain related to endometriosis is only felt in the reproductive organs. Although other parts of Endo Diary asserted that

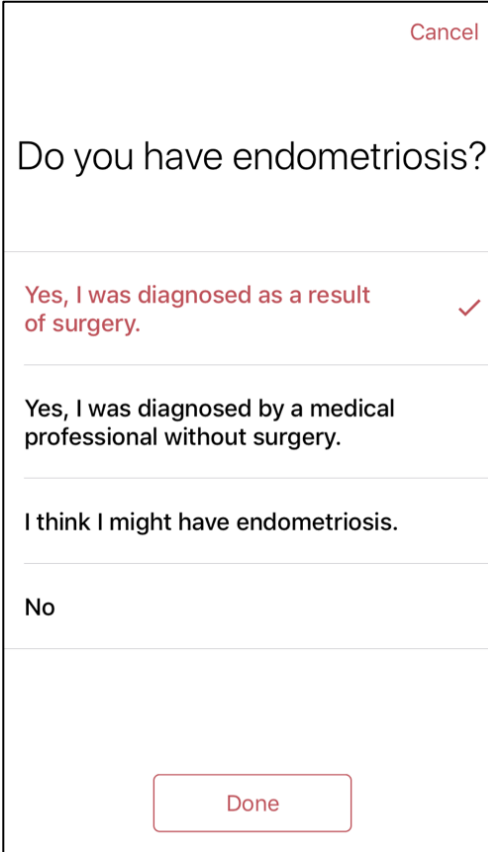
endometriosis could cause pain in other bodily locations (discussed previously), the uterus was visually constructed as the ‘essence’ of endometriosis. Images of the uterus (a potent cultural symbol) were used frequently and tended to be highly salient, including when it was used as a watermark across the top of several screens to denote that the uterus was relevant to all aspects of endometriosis (Machin & Mayr, 2012). Therefore, Endo Diary’s information and tracking options discursively used the uterus to minimise the contradictory messages within the app and clearly constructed endometriosis as a disease of the reproductive organs.

As with other apps, Endo Diary constructed menstruation as a central feature of endometriosis, without making it clear exactly what aspects of menstruation are linked to endometriosis. Two of the five tracking components on Endo Diary related to components of menstruation: Bleeding Profile (denoted by an image of three drops of pink blood) and Blood Clot (denoted by a cross-section of vein revealing pink blood cells spilling out). When pressed, the Bleeding Profile button prompted users to record their menstrual flow as either none, spotting, normal (described as ‘regular bleeding’), or heavy (described as “dark color [sic] of blood and is thick”), again evoking ideas that dark and thick menstrual blood are unhealthy and abject. The Blood Clot button offered users a simple categorical choice between Yes and No, with no guidance for users about what a blood clot is, or how it would be identified. Despite using the vein imagery, it is unlikely that Endo Diary expected users to identify and record blood clots in their veins; it is more likely to be referring to thick and clotted menstrual discharge. Therefore, using a vague, more abstract image of a vein for Blood Clot rather than a more literal symbol depicting said menstrual discharge potentially reflects the cultural taboo prohibiting un-sanitised, literal depictions of menstruation (Ussher, 2006; Johnson-Robledo & Chrisler, 2013). While Pill Consumption could ostensibly be offering users the ability to track their consumption of pain medication, the Mini Game and other parts of the app constructed pills as part of hormonal therapy (discussed in Chapter 6).

4.2 Privileging biomedical and scientific knowledge about endometriosis

This multimodal analysis demonstrated that both biomedical and natural wellness apps drew on biomedical and biological scientific discourses to construct endometriosis as a physical disease of the female reproductive body. Constructing endometriosis as a disease placed it within the domain and control of biomedicine, in a process known as medicalisation (Sulik, 2009; Zola, 1972). In the West, biomedical discourses are powerful sources of authority about health and illness, and typically construct health problems as pathologies to be eradicated through expert medical intervention (Foucault, 1975; Lupton, 2012). Once a problem is medicalised, explanations and solutions that see the problem as non-medical, normal or socially constituted are constrained (Sulik, 2009).

One effect of medicalising endometriosis is that apps constructed people with endometriosis as patients within a doctor-patient relationship (Conrad & Schneider, 1980). The “doctor-patient” dynamic permeated both biomedically and natural/wellness-oriented apps, demonstrated by constructions of medical doctors and other health professionals (including naturopathic nutritionists) as experts in what is and is not pathology, while women’s experiential knowledge about their bodies was constructed as irrelevant or unimportant. Several apps reflected traditional biomedical doctor-patient dynamics by positioning doctors as the gatekeepers of deciding whether a patient should receive an endometriosis diagnosis (and therefore access to medical support). For example, Flutter frequently reminded users that “nothing can replace a visual examination by a trained endometriosis specialist”, which prioritised the medical knowledge doctors are trained to use over experiential knowledge of people with endometriosis and other non-biomedical experts. Phendo also positioned medical professionals as gatekeepers of deciding who has endometriosis or not, demonstrated by the screenshot shown in Figure 8 asking users “Do you have endometriosis?”:



Cancel

Do you have endometriosis?

Yes, I was diagnosed as a result of surgery. ✓

Yes, I was diagnosed by a medical professional without surgery.

I think I might have endometriosis.

No

Done

Figure 8. Screenshot of question "Do you have endometriosis?" in Phendo. Users were able to select one of four answers, and their selection became highlighted in pink. Reproduced with permission.

Phendo only allowed users to answer in the affirmative when they had received a formal surgical or non-surgical diagnosis by a medical professional. Otherwise, users were only able to say that they “think [they] might” have endometriosis, minimising their ability to speak authoritatively about their bodily experience. Furthermore, visual confirmation of endometriosis in the body (via laparoscopic surgery) was privileged as the ideal type of diagnosis over a non-surgical medical diagnosis, reflecting the importance placed within medicine on seeing visible evidence of disease to corroborate and legitimise women’s reported suffering. This reflects historic and contemporary medical tendencies to disbelieve women who report physical symptoms in the absence of material ‘evidence’ for them, which

increases the likelihood that women are offered psychogenic explanations instead (Jones, 2015; Young, Fisher & Kirkman, 2018).

Drawing on biomedical and biological discourses to construct endometriosis ultimately encouraged women to see themselves as medicalised subjects who could rely on biomedical practitioners and other natural and wellness experts to understand and manage their endometriosis. Women were typically discouraged from making their own decisions about their endometriosis management in ways that potentially reduced their agency. For example, a video in Endo Diary depicted Rose, a woman with endometriosis, describing how she decided to stop taking her prescribed hormonal therapy because her symptoms had resolved. She constructed her agential act as incorrect by describing how stopping caused her pain “to come back ten times worse”. She enacted a medicalised subject position by stating that she is now “definitely more disciplined” in taking the medication prescribed to her by her doctor. Very occasionally, apps encouraged users to rely on their own experiential knowledge and intuition, such as when Endo Empowered encouraged users to “tune inward and really connect with your body and what it needs from you”. However, elsewhere in the app, Endo Empowered minimised the agency afforded to users in this statement by positioning Melissa Turner (the app developer) as the expert about women’s unruly bodies. In this way, women with endometriosis were positioned as owners of unruly reproductive biology that is out of their control, which could function to exonerate users from feeling responsible for causing their symptoms (Ussher, 2006).

4.3 Pathologising women’s bodies and behaviours

However, other parts of the app positioned women as responsible for using the expert advice to bring their reproductive bodies under control. Apps frequently drew on discourses of the female body as simultaneously dangerous and polluting while being a natural and

essential part of ‘good’ womanhood (Grosz, 1994; Ussher, 2006). As discussed, apps constructed endometriosis as dangerous and debilitating while constructing non-dysfunctional female bodies in highly positive terms. For example, MyFLO characterised female endocrine systems as homeostatic, closed-circuit systems that always need to remain ‘balanced’ if women are to access the “superpowers” afforded by female hormones (Roberts, 2007). While seeing positive attitudes towards menstruation may be validating and empowering for users (Chrisler & Johnston-Robledo, 2018), MyFLO did not offer this subject position to women with endometriosis and other hormonal problems. Instead, having symptoms was construed as evidence of abnormality and poor health; a frequent refrain across MyFLO was that “while symptoms [mood swings, heavy bleeding, PMS] are common, they’re definitely not normal”. Therefore, women with endometriosis experiencing such symptoms were offered a subject position of being unhealthy and were precluded from feeling positive about their menstruation, unless they undertook work to “normalise” and balance their bodies.

Moreover, constructing women with ‘balanced’ female hormones in ways aligning with hegemonic feminine ideals functioned to construct endometriosis as caused by acting outside of the constraints imposed by female biology. Given that dominant social discourses construct the functional female reproductive body as central to taking up the ‘woman’ subject position, endometriosis was constructed as dysfunction of both the reproductive body and femininity (Ussher, 2006). Again, MyFLO demonstrated how apps encouraged women to fix their reproductive bodies by shaping their behaviours and lifestyle decisions around their biological constraints. MyFLO owner Alissa Vitti constructed the heavy demands placed on women in the modern world in the following extract:

As women, we’re trying to do it all, be it all and have it all. And in that pursuit, we end up with the never-ending to-do list, putting everyone else’s needs first, and basing healthy living on what magazines say. Instead, our health as a whole gets worse.

We're dealing with debilitating period issues and a growing epidemic of chronic conditions – like fibroids, endometriosis, ovarian cysts and premature ovarian failure (A. Vitti, personal communication, June 20, 2019).

Vitti's comments about women's "never-ending to-do list" and "putting everyone else's needs first" are welcome acknowledgements of the disproportionate burden placed on women to perform paid and unpaid work within patriarchal, industrialised Western capitalist economies (Riley et al., 2018). It is unclear what type of magazines Vitti was referring to, but she appeared to be challenging discourses within these magazines that women can be healthy while trying to "do it all, be it all and have it all". Therefore, Vitti may have been challenging both feminist and postfeminist discourses that commonly minimise the impact of female biology on women's ability to freely participate in the workforce (Roberts, 2007). However, Vitti proceeded to construct endometriosis as part of a "growing epidemic" of chronic gynaecological conditions directly caused by women choosing lifestyles that do not adhere to the constraints posed by their reproductive bodies. Nonetheless, MyFLO did not advocate for women to withdraw from working; instead, it heavily idealised the postfeminist ideal of the flexible, autonomous working woman who becomes more productive by optimising her menstrual cycle (Riley et al., 2018). In this way, MyFLO reflected both gender essentialist and postfeminist discourses by encouraging women to embrace their femininity (including its limitations) by offering interventions that focused on the constraints posed by the specific requirements of the female endocrine system (discussed further in Chapters 5 and 6).

4.4 Summary

Apps drew on dominant biomedical and biological discourses in visual and linguistic content to construct endometriosis as a disease located within the individual female reproductive body. Endometriosis was often constructed in contrast to 'normal' menstruation,

which drew on discourses that menstruation is both abject and natural. Endometriosis (and its associated symptoms) was always constructed as unnatural, and as more abject than normal menstruation and reproductive bodies, and there was evidence of apps discursively trying to separate a monstrous endometriosis from the self. These constructions meant that women with endometriosis were encouraged to see their bodies as abnormal, unhealthy, abject and inherently flawed. Constructing endometriosis as a disease located it as a medical problem best understood and managed by either biomedical professionals or natural/wellness experts, who also drew on scientific discourses to support their claims of authoritative endometriosis knowledge. Apps often endorsed a doctor-patient dynamic, which sometimes positioned women as passive recipients of care. More commonly, users were encouraged to actively manage their endometriosis by better managing their reproductive body.

5 Endometriosis as Confusing and Bad: Motivating Users to Self-Track

This chapter demonstrates how endometriosis apps encouraged users to undertake self-surveillance and self-tracking. I show how apps draw upon two different but complementary constructions of endometriosis. First, I show how apps used linguistic strategies and imagery to construct endometriosis as confusing, drawing on a broader discourse of women's bodies as confusing and enigmatic. While there were differences in who was constructed as having knowledge, apps were united in their positioning of women as lacking knowledge about their confusing bodies. Second, I demonstrate how apps used colour, linguistic strategies and app self-tracking design to construct endometriosis as all-encompassing and severe; as affecting every aspect of a person's life and causing significant distress. Finally, I show how these two constructions worked together to motivate users to undertake self-monitoring and tracking of their embodied experiences in order to gain knowledge and understanding of their confusing and all-encompassing endometriosis.

5.1 Constructing endometriosis as inherently complex and confusing

5.1.1 Endometriosis as agentic; evading understanding and capture.

Apps often assigned endometriosis sentient qualities to construct it as an agentic entity acting upon the body. Several apps used metaphorical language to describe endometriosis as a kind of monstrous villain. The Endo Empowered app offered users the opportunity to “escape from the clutches of endometriosis”, while Flutter published an article describing endometriosis as “your worst enemy”, which actively “clenched its grip” on the author's body. Similarly, apps positioned people in combat with endometriosis; another article republished by Flutter described women as “battling” an endometriosis, while an article republished by Endo Diary suggested that endometriosis can make people feel their “body is against” them. By applying highly negative metaphors of monsters and war to

endometriosis, apps reinforced dominant meanings about the female reproductive body as monstrous and threatening (Ussher, 2006) These metaphors functioned to ascribe endometriosis agency by evoking images of endometriosis emerging from within the uterus to actively invade the rest of the woman's body and ruin her life.

Some apps also constructed endometriosis as enigmatic and elusive. Endo Diary referred to endometriosis as “invisible”, “unpredictable” and described it as having a “variety of symptoms commonly associated with other illnesses, which makes misdiagnosis common”. This worked to construct endometriosis as having inherently complex characteristics, making it difficult to see and understand. Similar strategies were seen in Flutter, which republished a transcription of a speech given by US-based gynaecologist Tamer Seckin at the Endometriosis Foundation conference in 2013. While describing how endometriosis cells embed in the peritoneum (the membrane lining the abdominal cavity), Seckin produced endometriosis as agentic and elusive, shown in the following extract:

That is why the endometriosis symptoms are very elusive. It does involve every part of the pelvis and vagina all the way to the diaphragm... These two things are talking to each other, signalling each other and the body is kind of fooled with this foreign material. And it is like graph versus false [sic] reaction. It says, "Finally, hey you're mine, I'll save you". And exactly, he [a cell] is like a little mouse there, this is early, catch out every time. That little thing survives and anchors. The body makes it, owns that gland and becomes part of that peritoneum. But that gland will work against the body, against the peritoneum, against every organ it is adjacent to.

Seckin discursively produced endometriosis as separate from the rest of the body by calling biological cells involved in the development of endometriosis “foreign material”. He also produced these cells as agentic by using personifying language to describe how they talk and

signal to each other in ways that “fool” the body. This agency was reinforced by Seckin’s construction of the resulting endometrial gland cell as a “little mouse” that actively “survives” and “anchors” to the peritoneum to work “against the body” and cause endometriosis symptoms. Seckin used a male pronoun to describe the mouse-like endometriosis cell, which reflected a biomedical discourse of male agency and female passivity within reproduction, such as how male sperm is constructed as agentially and aggressively entering the passive female egg (Martin, 1991). In this way, Seckin constructed endometriosis as an agentic subject evading capture and causing “very elusive” symptoms, which reproduced dominant biomedical discourses that endometriosis is innately confusing and enigmatic (Seear, 2014). This potentially functioned to absolve doctors who are unable to locate or remove endometriosis of responsibility.

5.1.2 Lexical suppression of biomedical actors.

Biomedically oriented apps constructed endometriosis as confusing and elusive in ways that acknowledged the limited knowledge about endometriosis without challenging their own knowledge and credibility claims. Apps like Endo Diary and Flutter did not explicitly comment on the limits of biomedical knowledge about endometriosis, but they acknowledged the difficulty many women report in obtaining a diagnosis of endometriosis (Culley et al., 2013). However, apps used discursive strategies to avoid positioning doctors as responsible for diagnostic delays or misdiagnosis, despite the fact they are active participants in medical diagnosis and surgery. For example, they linguistically obscured the actions of doctors by using passive clause structures with no clear actors, demonstrated by the following extract from Flutter, titled “Why is it so critical to raise awareness about endometriosis?”:

Endometriosis is often misdiagnosed, and the consequences range from living in pain to unnecessary surgery such as appendix removal. Therefore, it's critical to raise awareness to prevent the needless suffering of millions of women worldwide.

Human actors are notably absent from Flutter's statement. Instead, Flutter used passive verb constructions like "endometriosis is often misdiagnosed" leading to vague consequences like "unnecessary surgery". This lexical suppression obscured both the medical actors involved and the power relations occurring during these social processes of misdiagnosing people and performing surgery upon them. The reference to the "needless suffering of millions of women worldwide" reinforced the construction of endometriosis as a severe and all-encompassing condition (discussed further in section 5.2) without addressing the agents and sociocultural factors and involved in such suffering. Flutter did not make it clear who should be doing the awareness raising, or who needs their awareness raised. Indeed, there was a marked absence of suggestions from the apps that doctors could undertake more research and education to improve the care they provide to women with endometriosis. By describing women with endometriosis as passively suffering, Flutter's statement drew on traditional biomedical discourses that position them as passive recipients of medical intervention.

Such passive grammatical positioning was also demonstrated in Endo Diary, which republished an article that described the difficulty of getting doctors to believe or diagnose endometriosis. One line of this article read: "Not only must we try to make our doctors understand something neither of us can see...". Using the adjunct verb 'try' positioned women seeking help for symptoms as attempting to act rather than succeeding and positioned doctors as the most agentic in the encounter (Machin & Mayr, 2012). It further reinforced that women's experiential knowledge is not legitimate or scientific, especially in the absence of visual evidence of pathology (Jones, 2015). The statement also placed full responsibility

for understanding endometriosis on the person seeking help and positioned doctors who do not understand as a natural, expected result of endometriosis being invisible and confusing.

5.1.3 Encouraging biomedical intervention.

For apps with a biomedical orientation, constructing endometriosis as inherently confusing and elusive exonerated biomedical professionals from having limited knowledge about endometriosis. However, it simultaneously enabled them to position women with endometriosis as lacking knowledge and being confused about their bodies. These opposing subject positions were demonstrated by a cartoon-style video published by Endo Diary that reported findings from an unspecified ‘international survey of women’ (Figure 9). The video depicted the main character (a woman in a green top) as embarrassed, confused and sad throughout. Figure 9.a depicted her standing with blushing cheeks and a bowed head in front of three smiling medical professionals standing in a dominant pose with hands on their hips. The image (including the capitalised, highlighted word ‘ABNORMAL’) and accompanying narration constructed women with ‘abnormal’ reproductive bodies as too embarrassed to visit medical professionals but positioned women who do not overcome their shame as wrongly missing out on friendly and authoritative medical knowledge and support. The video also positioned non-biomedical knowledge as unreliable and reinforced that doctors alone knew about endometriosis. Figure 9.b depicted three cartoon women (identified by the narrator as family and friends) telling the main character “It will stop after you have a baby” and “That’s just normal”, reflecting some of the often inaccurate and unhelpful advice women with endometriosis report receiving from both doctors and others (Culley et al., 2013).

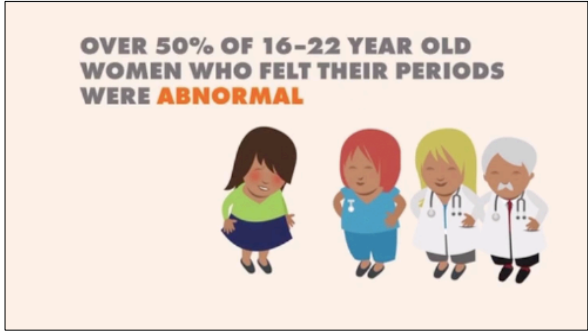
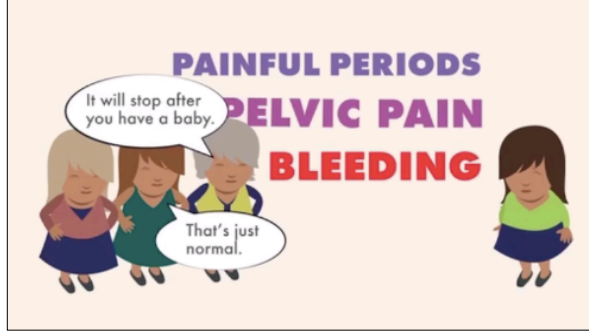
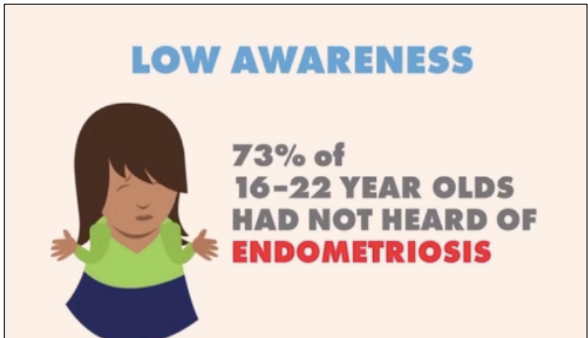

<p>a) [0:23 seconds]</p>  <p>N: "More than half of women of women aged 16 to 22 who felt their periods were abnormal had not seen a doctor".</p>	<p>b) [0:35 seconds]</p>  <p>N: "50 percent of 16 to 22 year old women rely on family and friends to judge what is normal."</p>
<p>c) [1 minute 38 seconds]</p>  <p>N: "Results show that there is a very low awareness of the condition. Less than half of the women surveyed knew of endometriosis and seventy three percent of 16 to 22-year olds have never even heard of it."</p>	<p>d) [1 minute 56 seconds]</p>  <p>N: "If left untreated, endometriosis can damage a woman's internal organs and compromise her fertility."</p>

Figure 9. Four screenshots of frames from the video titled "How common is endometriosis" from Endo Diary. Description includes time point frame appeared in video and the sentence being narrated (N) when frame was displayed narration. Reproduced with permission.

Figure 9.c reinforced this positioning by depicting the character below the salient words 'LOW AWARENESS' in blue lettering while holding her hands up and shrugging, a gesture commonly used to symbolise a lack of knowledge. Figure 9.c also used bright red lettering for the word 'endometriosis'; this kind of red has historically been associated with aggression, vulgarity and energy, reinforcing the idea that endometriosis is intense and bad

(Kress & van Leeuwen, 2006). This was reinforced by Figure 9.d, which depicted the character being informed about the risks of endometriosis by a medical professional, shown pointing to an image of a cross-sectioned female body while the video's narrator stated that untreated endometriosis can "damage a woman's internal organs and compromise her fertility", producing endometriosis as causing long-term injury and dysfunction, and reflecting dominant discourses that one of the worst aspects of endometriosis is the threat it poses to fulfilling normative ideals that women reproduce (Seear, 2009c).

Endo Diary's video used words and images to construct women experiencing symptoms of endometriosis as lacking essential knowledge about their bodies, and biomedical professionals as the only people with this knowledge. The app developers also positioned the app as a source of knowledge by stating in the last screen [not shown] that "women experiencing extremely painful periods or chronic pain should seek advice from their doctor". However, encouraging women to seek biomedical assessment and treatment ignored the evidence that women report doctors normalising their endometriosis symptoms for several years before they receive a diagnosis and support (Culley et al., 2013). Moreover, positioning women's experiential (non-biomedical) knowledge as unreliable while simultaneously encouraging users to use that knowledge to record data about their bodily experiences presented a contradiction. As will be discussed in subsequent sections, apps reconciled this by constructing self-tracking as something women can do to support others with more knowledge (such as biomedical professionals, researchers and app developers) to make sense of the data, and thus their experiences, for them.

5.1.4 Endometriosis as too confusing for biomedicine.

In contrast, apps drawing on natural health discourses constructed endometriosis as too confusing for mainstream medicine to understand by challenging biomedical knowledge

claims about managing endometriosis. For example, Endo Empowered encouraged users to join a Facebook group called “Rebellious Endometriosis Sisters” by asking:

Are you tired of hearing that surgery, hormone treatments and more painkillers are your only options? Have you tried these methods before, and they are just not serving you or have left you worse off?

This statement constructed biomedical interventions as both insufficient and harmful. Using the word “rebellious” evoked a sense of shared resistance by “endometriosis sisters” against the dominant, oppressive power of the medical establishment constructed as responsible for causing said harm. This sense of resistance was reinforced by an email sent from Endo Empowered owner Melissa Turner (personal communication, May 8, 2019) to app users, suggesting that biomedical endometriosis knowledge caused confusion among women with endometriosis, shown in the following extract:

I know how frustrating it can be when you desperately want answers and yet somehow, they don't seem to appear. You search through the internet, staying up until 3 am in the morning, tears streaming down your face...just searching and hoping that somehow, something miraculous will pop off the screen and guide you on what to do next. You try all the various google searches that spring to mind and you try to dig deeper but in your gut, you know there has to be more and there has to be some kind of answers. All the while, the pain keeps throbbing and those dreaded fearful thoughts keep churning around in your head. Maybe it is spreading?... maybe I am going to need a bowel resection?... maybe I just need another surgery?

Turner used this scenario to construct endometriosis as something so poorly explained by mainstream knowledge that users are left desperate for information about how to manage their endometriosis-related pain and anxiety. She used emotive imagery to position her users

as highly distressed, frustrated, fearful and as needing guidance “on what to do next” because they have only received problematic biomedical knowledge and offers of unwanted interventions (i.e. a bowel resection and ‘another surgery’) that have been unsuccessful on at least one previous occasion. Notably, this is one of only a few acknowledgements across the apps that living with endometriosis has non-physical components and constructs women as thinking, feeling people rather than just people with a diseased physical body. This strategy also constructed endometriosis as all-encompassing and severe (discussed in section 5.2).

In the next part of the email, Turner used a puzzle metaphor to construct endometriosis as a mystery to both biomedical professionals and people with endometriosis:

I want to give you a pillar of hope sweetheart because I have a depth of knowledge about endometriosis that took me over 7 years to learn and those insights are possibly those missing puzzle pieces that you are missing. It could be just a few miracle pieces that you need to add to the puzzle that you have already started, or it could be one ultimate piece that solves everything in one go. Either way sweetheart... please know that you are not alone in this and that I can help (M. Turner, personal communication, May 8, 2019).

Turner suggested that endometriosis management is a puzzle that users cannot hope to solve using only experiential knowledge or biomedical knowledge. Turner constructed her own products and services as the “miracle” and “missing puzzle pieces” required for “solving” endometriosis. She referred to her seven years of learning about natural endometriosis management to establish her credibility for providing these services and used authoritative language to position women as hopeless (i.e. “I want to give you a pillar of hope”) without her help. Her frequent use of the endearment “sweetheart” may be an attempt to make users feel seen and understood in contrast to their negative and impersonal experiences within

biomedical encounters but also functioned to position users as less knowledgeable about their endometriosis experiences than her.

More broadly, the MyFLO app constructed androcentric medical and scientific knowledge as failing to understand the “unique biochemical needs” women have. MyFLO often constructed biomedicine as minimising female hormonal problems, or offering inadequate, unhealthy or ‘dangerous’ treatment options, such as hormonal contraception or antidepressants. For example, MyFLO owner Alisa Vitti shared in an introductory email that when she was diagnosed with polycystic ovary syndrome (PCOS) that the “only answer [she] got for managing it [was] a lifetime of medications” (personal communication, June 18, 2019), while another email reinforced the idea that doctors will offer inadequate support for abnormal hormone levels:

Now, I know you may not think that mood swings, cramping, headaches, backaches or breast tenderness are a big deal. Maybe your doctor has even told you that, while some of your hormonal levels are out of normal range, that you can simply control them with the Pill (A. Vitti, personal communication, June 22, 2019).

In this extract, Vitti constructed female hormone levels as something that can be normal or abnormal, with abnormal levels causing bodily changes that people should experience as a “big deal”. This reinforced the construction of female biology as abject, discussed in Chapter 4. Vitti positioned users with ‘abnormal’ hormones and bodily experiences as unknowledgeable and confused by their bodies by implying that they “may not think” about their bodies correctly. By constructing doctors as offering simple, incorrect solutions such as the hormonal contraceptive pill, Vitti constructed medical professionals and biomedical knowledge as lacking knowledge about endometriosis, and reinforced dominant discourses that female hormones are not simple to understand or control (Roberts, 2007).

For apps with a natural wellness orientation, constructing endometriosis and women's health as too confusing for biomedicine to understand functioned to reject the dominance of biomedical management for endometriosis while still locating endometriosis within a biological discourse. Therefore, natural wellness apps positioned themselves as having superior knowledge while still drawing on scientific research and biological discourses about endometriosis and female hormones as confusing. Vitti described herself as a "hormone expert" while Turner used the phrase "endometriosis expert". Both women referred to their naturopathic and nutrition qualifications, as well as their personal experiences with endometriosis (Turner) and PCOS (Vitti).

5.2 Constructing endometriosis as severe and all-encompassing

5.2.1 Linguistic strategies: overlexicalisation and extreme case formulation.

Apps also used a wide range of linguistic techniques to construct endometriosis as severe and all-encompassing. First, they used the discursive strategy overlexicalisation, repeatedly describing endometriosis using multiple synonyms (Machin & Mayr, 2012). Apps frequently described endometriosis as life-changing, all-encompassing, serious, devastating (Endo Diary), daunting, scary, overwhelming, challenging (Endo Empowered), debilitating, chronic, and painful (Flutter). As discussed previously, Flutter often described endometriosis as a monster or "your worst enemy". A video published by Endo Diary introduced Rose (a woman who managed her endometriosis through long-term hormonal therapy) as an "Endo Survivor", again drawing on quest or war discourses to construct endometriosis as an aggressive invader or negative challenge to overcome.

Apps also emphasised how bad endometriosis is by using extreme words and phrases, known as extreme case formulation (Pomerantz, 1986). For example, apps presented case studies of people with severe experiences of endometriosis as typical. Endo Diary

republished a piece (without appropriate acknowledgement) called “10 Things You Might Not Understand About Endometriosis”, originally written by endometriosis blogger Shireen Hand (2017). While Hand’s article acknowledged that some people experience mild symptoms, she primarily emphasised the extreme end of endometriosis experience:

Endometriosis is an all-encompassing disease. It isn’t just a bit of pain while you’re on your period. Endometriosis can affect every part of your life. It can cause problems every day of your reproductive life and can continue to do so after menopause.

Hand’s description produced all-encompassing, severe symptoms as an objective, essential property of endometriosis rather than a “product of the interaction or the circumstances” (Pomerantz, 1986, p. 220) of a particular person’s experience, such as the level of social support available to a person. Pomerantz considered that such extreme formulations attributed cause to the object itself; in this way, distress felt by someone with endometriosis becomes caused by the endometriosis within the individual body, which minimises how social factors contribute to distress. It also positioned people with endometriosis as being controlled by their endometriosis, and always suffering.

However, Hand also used extreme case formulation to defend against challenges that endometriosis is not severe. She rejected a competing construction of endometriosis as ‘just’ period pain by formulating endometriosis as something that affects “every part of your life” for “every day” of a person’s reproductive and menopausal life. Hand also used the word ‘can’ as to soften the extreme position being formulated, which can be a discursive way for speakers to pre-empt potential challenges without losing the power of the claim itself (Edwards, 2000). The full article aimed to help people without endometriosis understand “the impact endometriosis can have on a woman’s life” and included rebuttals of conventional social constructions about endometriosis (i.e. that hysterectomy, pregnancy or behavioural

changes can cure endometriosis). Therefore, using extreme case formulation functioned to resist the frequent normalisation and trivialisation that people with endometriosis experience from biomedicine and wider society (Seear, 2009a), exercising what Foucault (1977) called counter-power. Within chronic illness communities, people often construct particular illnesses as severe to offer themselves competing subject positions of being credible and deserving of support. However, Hand's article was one of the few examples of how extreme formulations and language were used for this purpose and took on a different discursive meaning when republished by Endo Diary alongside other, always severe case examples. Therefore, positioning women as always suffering and desperate may function to encourage users to engage with specific app features and tools, such as self-tracking.

5.2.2 Breadth of self-tracking features related to endometriosis.

The design and content of app self-tracking affordances reinforced that endometriosis is all-encompassing and severe, through the sheer breadth of options made available for users to track and consider relevant to endometriosis. Four out of five apps offered users the ability to quantitatively record various aspects of their physical, emotional and behavioural experience each day, even though non-physical experiences were rarely included in constructions and definitions of endometriosis. The amount of tracking varied across apps; Endo Diary offered only five tracking options, while Phendo and Flutter offered the ability to track multiple components of multiple issues, which constructed endometriosis as something that affects multiple aspects of a person's internal and external life. Tracking focused primarily on two categories: bodily experiences and behaviours. Tracked bodily experiences included pain, bleeding, gastrointestinal and urinary issues, mood and self-esteem. Behaviours included sex, productivity, sleep, and 'self-management' behaviours like exercise, consumption of food, medication, hormones, supplements, and activities.

Phendo demonstrated how endometriosis was discursively constructed as all-encompassing through app self-tracking affordances. As Phendo is an active research project aiming to collect data about endometriosis, it avoided explicitly defining or describing endometriosis. However, the tracking components of the app still communicated that endometriosis is a pervasive part of a person's life. There were two separate tracking components: "Track this day" and "Track this moment". Phendo described "Track this day" as a place to "review all your moments and review your overall day, self-management techniques, sex, diet, exercise, hormones and supplements", and "Track this moment" as a place to "log a specific occurrence of pain, GI/urinary, or other bodily symptoms...mood, bleeding and medications". In total, there were sixteen tracking questions across the two components, although users were able to remove any questions they did not wish to track in the settings.

The two tracking components worked together to construct endometriosis as something that people should think about, monitor and record on a moment by moment basis. One of the questions in the "Track this moment" component asked users "What are you experiencing", shown in Figure 10. Users were able to select and record over twenty sensory and bodily experiences not traditionally considered to be relevant to endometriosis, such as asthma, eczema, fever, and blurry vision. Although Phendo constructed these as co-occurring conditions, rather than part of the disease of endometriosis, the breadth of options nonetheless functioned to encourage users to consider all aspects of their embodied experiences as potentially implicated in their experience of endometriosis, and therefore ideally monitored and tracked. Furthermore, the interface offered users the ability to select mild, moderate or severe only once, even if different experiences were experienced at different intensities. This may contribute to users feeling compelled to select an overall severity option that inadequately represented their experience.

The self-tracking features of apps also constructed mood swings and negative feelings as central features of endometriosis, despite primarily describing endometriosis as a physical disease. Apps offered tracking of feelings, emotions and mood in the same way users tracked other endometriosis symptoms. On one level, acknowledging that the experience of endometriosis involves emotions and feelings alongside physical experiences may validate women with endometriosis who have previously had non-physical parts of their experience minimised by biomedical professionals (Culley et al., 2013). However, apps provided little explanation for how endometriosis related to mood or why users should track their emotions and feelings. They also emphasised negative emotions more than positive or neutral emotions, reinforcing that negative emotions are more common in people with endometriosis. This was demonstrated by Figure 11, which shows screenshots from Phendo's "How is your mood?" tracking question. Users could choose from ten 'positive' and twenty 'negative' feelings and emotions. In this way, self-tracking options encouraged users to attend to and monitor their feelings and emotions (especially negative ones) and then attribute them to endometriosis. In conjunction with tracking so many other features of daily experiences, tracking mood to this degree constructed endometriosis as negatively affecting most daily physical and emotional experiences. The emphasis on tracking negative emotions combined with Phendo's characteristic scientific aesthetic (discussed in Chapter 4) produced negative mood as a central part of the biological pathology of endometriosis.

Emotions and feelings were also constructed in ways that reflected underlying neoliberal and postfeminist discourses. Phendo's tracking options constructed mood as an internal, individual experience and provided little acknowledgement of social factors, reflecting neoliberal ideals of people as autonomous, rational, self-controlled individuals (Sanders, 2016). While a few options described relational emotions or feelings (i.e. affectionate, social, antisocial, isolated and lonely), most were decontextualized from the

factors that contribute to a user having a feeling or emotion. They also constructed being optimistic and productive as 'positive', reflecting neoliberal and postfeminist discourses that women should self-regulate their internal emotional states to ensure they remain happy and able to contribute economically to society (Rose, 1999; Riley et al., 2018). Other apps also drew on negative stereotypes of women's behaviour being controlled by her biology, demonstrated by Flutter offering tracking of the mood descriptor 'Bitchy' and MyFLO using the word 'hormonal' (Ussher, 2011). Next, I discuss how apps pathologised women's emotions using strategies other than self-tracking.

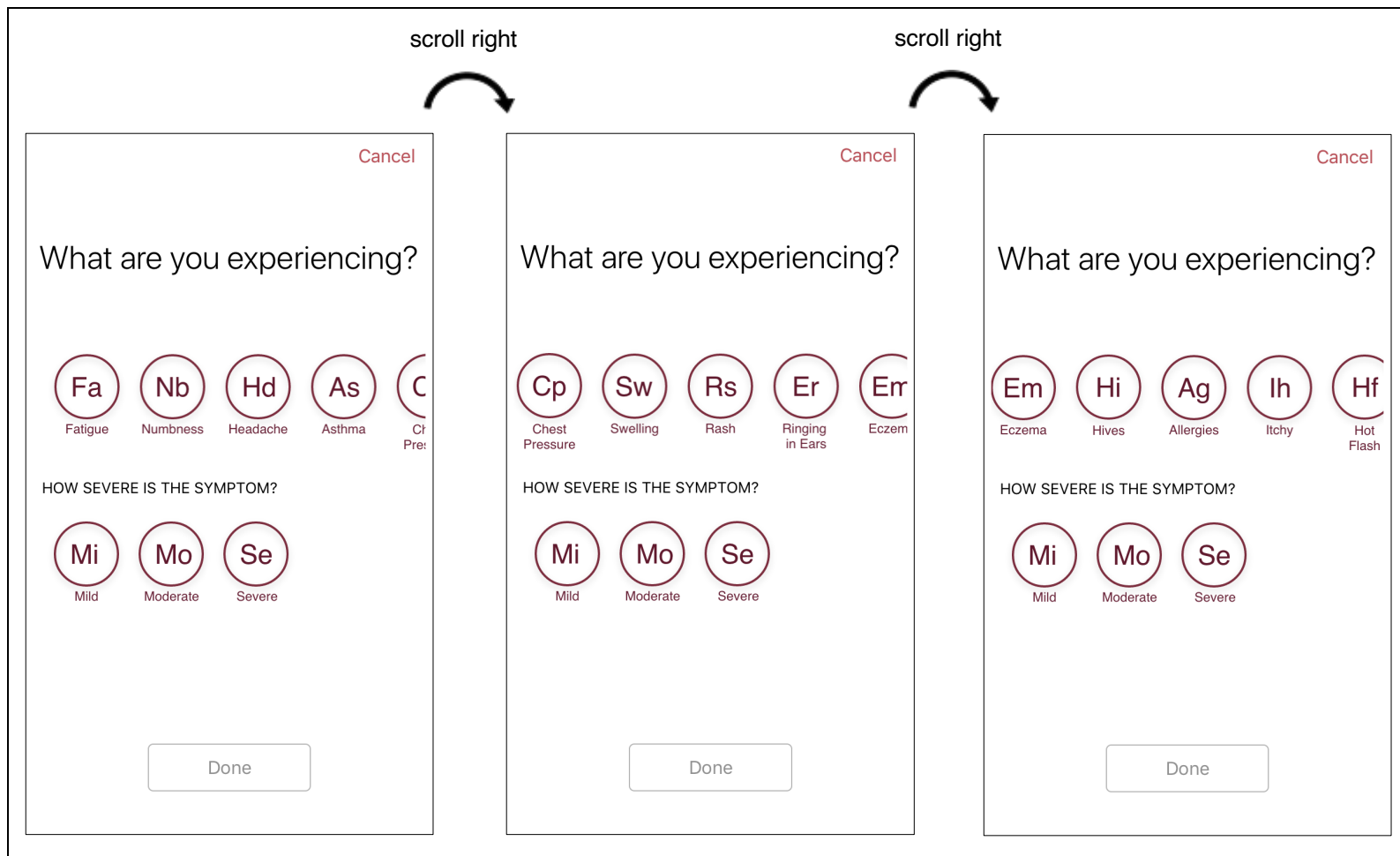


Figure 10. Three partial screenshots of the "What are you experiencing" question of the "Track my moment" section of Phendo. Users were able to select from 21 experiences and 3 levels of severity. Reproduced with permission.

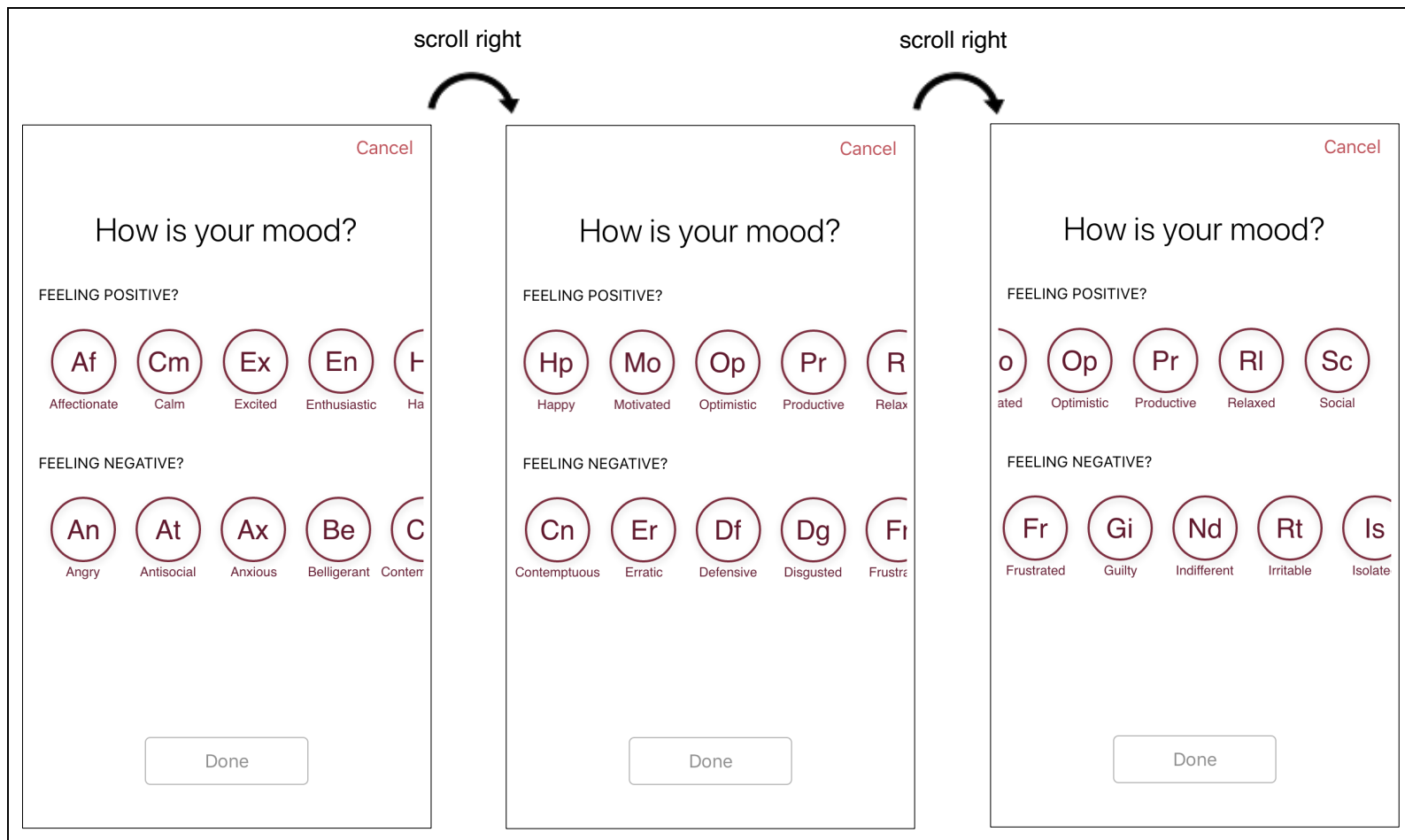


Figure 11. Three partial screenshots of the "How is your mood?" question in the "Track this moment" section of Phendo. Users were able to select from 10 positive and 20 negative feelings/emotions. Reproduced with permission.

5.3 Pathologising excessive negative emotionality

Apps often constructed endometriosis-related negative feelings as originating within the individual woman, ignoring the social factors shaping them. Some apps identified social factors shaping the psychological experience of endometriosis; for example, an article republished by Flutter titled “7 Celebrities Share their Struggles with Endometriosis” quoted celebrity Susan Sarandon encouraging people to break the “taboos and loneliness” related to endometriosis by “[being] understanding, show empathy, and don’t accuse her of being sensitive, delicate, or overly dramatic”. The article by Hand republished by Endo Diary also constructed negative emotions and depression as common in women with endometriosis because of the impact of the pain of endometriosis on women’s personal, work and social lives. However, these examples were infrequent and were typically written in republished articles rather than in the information or self-tracking offered by the app itself. They also did not explicitly attend to the stigma, silencing and alienation around endometriosis (and menstruation) that contributes to women’s isolation and distress (Culley et al., 2013).

Constructing emotional distress as originating within the individual enabled apps to construct women with endometriosis as excessively emotional, even while constructing endometriosis as all-encompassing and severe. Apps encouraged users to monitor their levels of negative emotionality for evidence that it had become excessive relative to the actual challenges posed by endometriosis. Additionally, apps often drew on a rhetoric of choice to construct users as choosing to feel excessively bad. For example, the first daily message sent to users from Endo Empowered advised them that it was the “first day of deciding to change how you feel”. Another email sent by Turner (personal communication, July 4, 2019) told users “Sounds odd, but the reality is, it is how we view things, that can have the most dramatic effect on our health” reinforcing that users should assess and modify their mental

state. A more detailed example is shown in Figure 12, depicting one of several Endo Empowered daily “inspiration” or “challenge” posts:

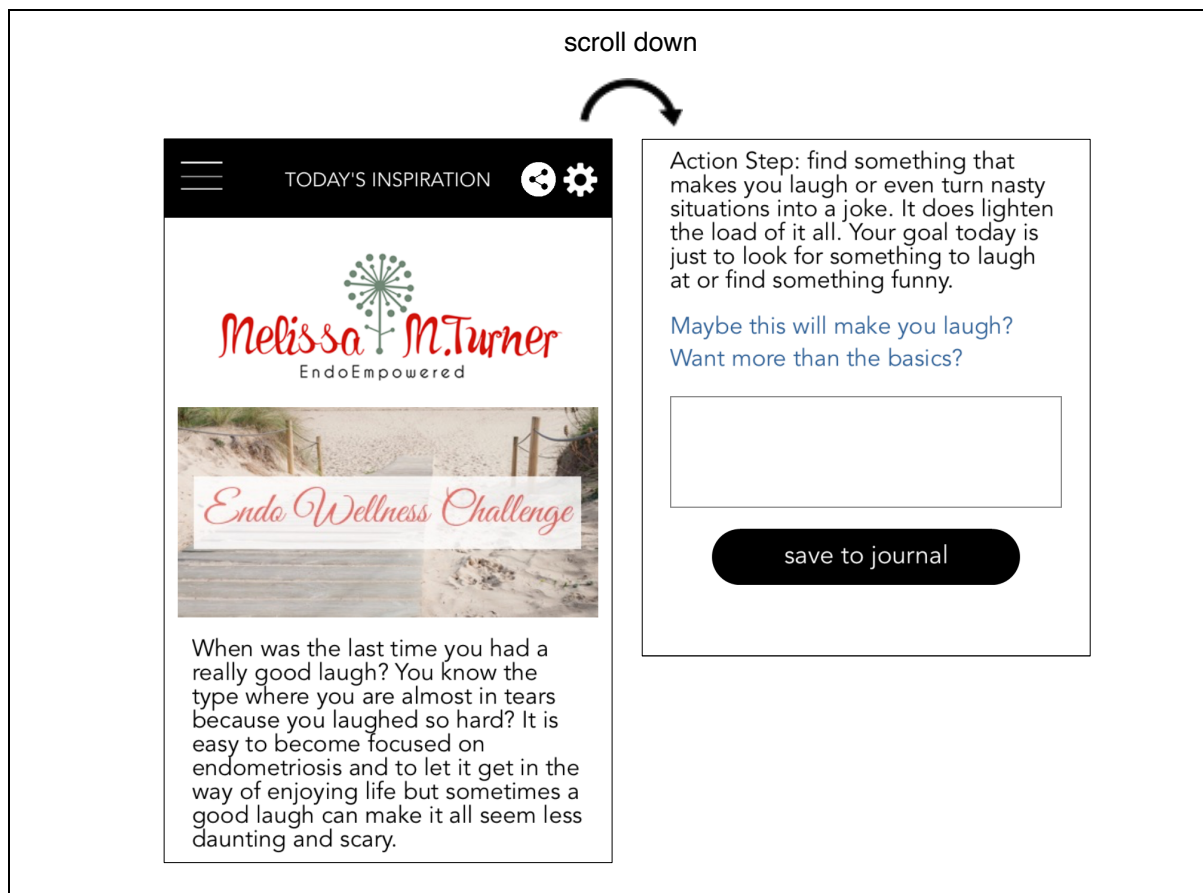


Figure 12. Day 15 of Endo Wellness Challenge of Endo Empowered. Reproduced with permission.

The screenshots depict the standard format used for all Endo Empowered challenges. The black panel with the words “Today’s Inspiration” sat above a logo for Turner, producing her as the author of the following inspirational advice. Below this, a photo image of a wooden boardwalk on a sandy beach was overlaid with the text “Endo Wellness Challenge” written in a pale pink, calligraphy-style font. The colour, text and image worked together to discursively reinforce the app as offering users a path away from the turbulence of endometriosis toward a gentle and calm life. The wording of the challenge communicated that endometriosis-related turbulence is partly caused by people with endometriosis excessively focusing on their

endometriosis and letting it “get in the way of enjoying life”. This not only constructed endometriosis and life satisfaction as mutually exclusive, it also positioned people as failing to resist the impact of endometriosis on their lives. Users were encouraged to see endometriosis as a heavy burden through the metaphorical injunction to “lighten the load of it all” by finding and paying attention to something funny or reframing a negative situation as a joke. Not only did the use of “it all” further produce endometriosis as all-encompassing, the challenge implied is that there is a healthy amount of negative emotions one should feel, reflecting social tendencies to pathologize women’s negative emotions (Ussher, 2011).

This and other Endo Empowered daily challenges reflected how the app drew on gendered discourses that women with endometriosis (or perhaps women in general) are prone to excess negative emotion, stress and poor self-worth (Facchin et al., 2016; Martin et al., 2011). For example, one challenge encouraged users to “dismiss the anxiety and worry for a few minutes if you can”, constructing users as perpetually in a state of heightened negative emotion. Another challenge encouraged users to increase gratitude by writing love notes to themselves, while another encouraged users to write “I AM ENOUGH!” on the mirror in watermark pen or lipstick to decrease their stress levels. The app offered limited justification for this recommendation, which communicated that women with endometriosis always have high stress levels and that this stress is caused by feeling they are not ‘enough’, although it was not stipulated anywhere what ‘enough’ is or who measures it. Therefore, the focus on lowering stress and anxiety levels in the absence of reference to external factors produced excessive negative emotionality as being internally generated within women with endometriosis and encouraged individualised responses.

In summary, the dual constructions of endometriosis as confusing and endometriosis as all-encompassing worked together to produce endometriosis as a highly distressing, central part of a person’s life that required further understanding. They also positioned women with

endometriosis as simultaneously lacking knowledge about their endometriosis but highly motivated to resolve and better manage it.

5.4 Encouraging self-tracking

Apps constructed inbuilt self-tracking features as offering users an opportunity to render their bodily functioning visible as a way to better understand endometriosis (Kressbach, 2018; Lupton, 2017). The apps elicited data about physical, emotional and behavioural functioning and rendered these experiences visible to both the user and app developer. They often manipulated the data using algorithms; MyFLO offered a rudimentary calculation of commonly recorded symptoms and experiences and recommended tailored treatments (both free and paid) to reduce them. These self-tracking features communicated that people cannot understand their body without insights afforded by the superior analytical ability of digital devices. This reflects the common assumption within scientific discourse (which is integral to digital health technologies) that accumulating and interpreting complex numerical data reveals objective, scientific (and meaningful) fact (Sanders, 2016).

The apps constructed collecting and visualising quantitative data as meaningful for users' understanding endometriosis in three ways. First, some apps constructed data collection and self-tracking as a way for users to understand and manage their own experience. For example, Phendo provided an "Insights" functionality that visualised data in two ways as a way for users to "potentially learn more about trends in your health". Figure 13 shows the data visualisation available after tracking four days of hypothetical data. Each tracked day was visualised through a three-part prong comprised of different colours and codes. It is questionable how meaningful these data visualisation graphics could be for users, given that they lacked a key to explain what individual colours, symbols, or patterns meant and relied on users remembering the 'physical element' code for each tracking component.

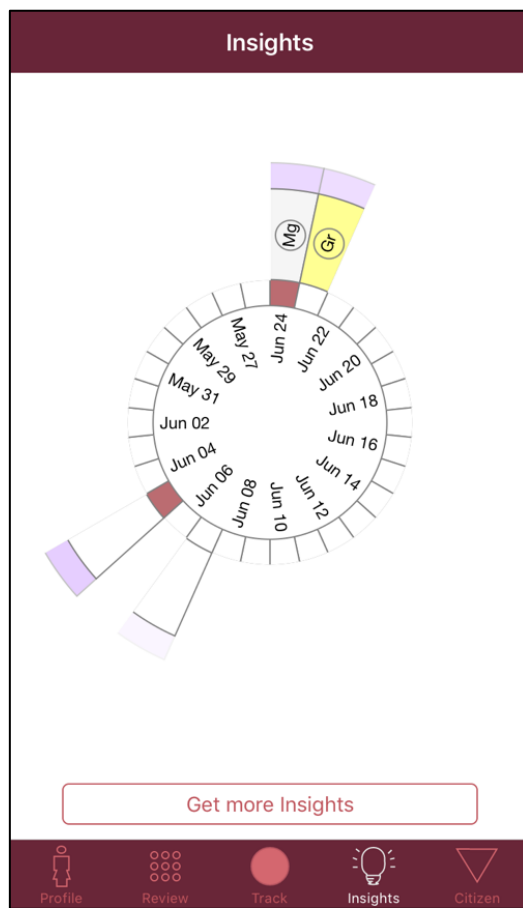


Figure 13. Screenshot of visualisation of tracked data in "Insights" section of Phendo.

Reproduced with permission.

Users could be emailed a more detailed visualisation by pressing the “Get more Insights” button, which used the same ‘physical element’ codes in multiple colours, along with different coloured lightning bolts and face ‘emojis’ (see Figure 14). Even once I deciphered the potential meaning of each symbol, it was unclear how tracking might render my hypothetical experience more meaningful. Similarly, Endo Diary offered visual ‘Charts’ to represent user’s tracked data, although all charts used a line graph that was meaningless for categorical data such as mood states and pill consumption. Nonetheless, these visualisation tools constructed collecting data about endometriosis as contributing meaningfully to women’s understanding of their endometriosis-related experiences. In this way, apps offered

users a shift from an unknowing subject position to a knowledgeable one. However, as self-knowledge was only possible by using app self-tracking features, apps also positioned people as unable to interpret their experiences and feelings without digital, expert intervention.

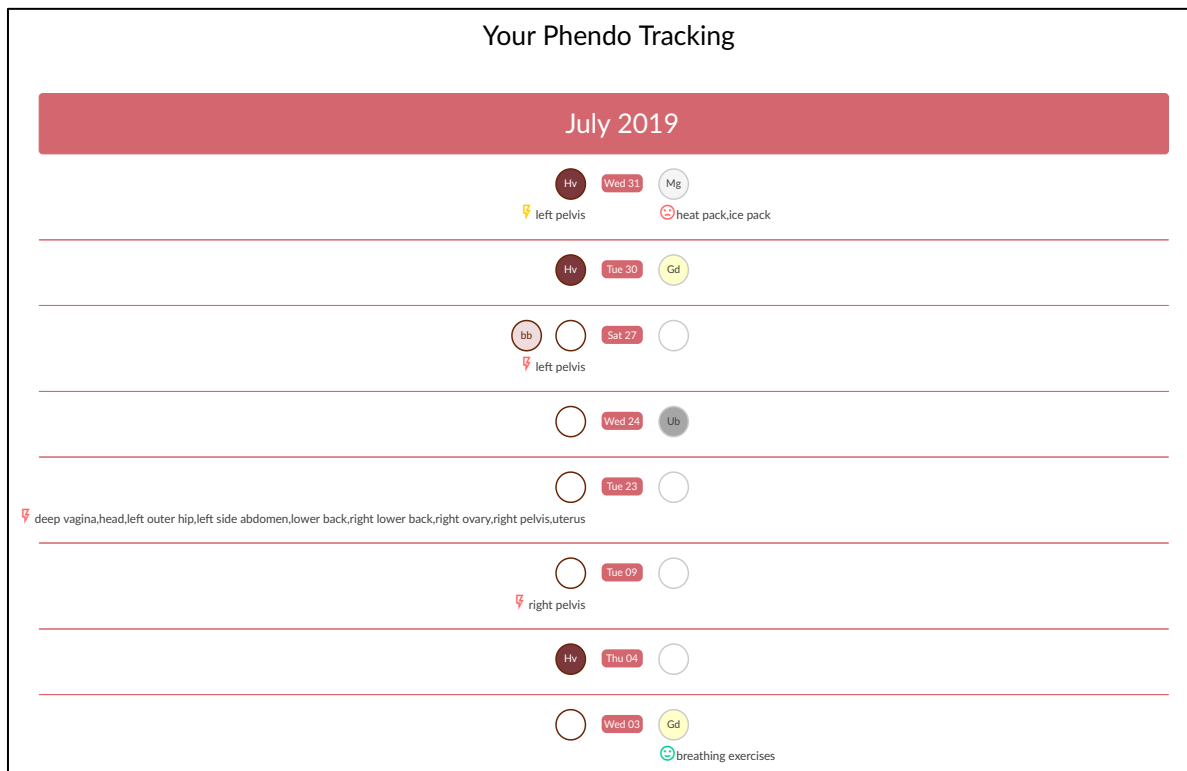


Figure 14. Partial screenshot of “Your Phendo Tracking” detailed visualisation of tracking data sent to Phendo user email upon request. Reproduced with permission.

Second, data collection was seen as a way for people with endometriosis to quantify their embodied experiences to more effectively communicate their experience with doctors to improve diagnosis and treatment outcomes. For example, Flutter offered a functionality for users to export 90 days of their journal records and the endometriosis self-diagnosis test to a PDF file that the app recommended should be taken to the doctor.¹ Figure 15 shows how

¹ The PDF export function did not work during the period of study, so it was not possible to analyse how the information was presented.

Flutter's "Track & Share" functionality explicitly encouraged users to share their daily tracking with their doctor because "data and communication are essential to ensure you feel your best". This message was reinforced by the cartoon illustration of a calendar and report containing a pink heart and surrounded by stars which constructed tracking as having positive and pleasant benefits for the user. The app screen appeared prior to registering to use Flutter, indicating that it aimed to encourage potential users to proceed with using the app.

Notably, the screen's text discursively produced tracking and sharing of both emotions and physical experiences as helping users to "feel their best" rather than managing or curing their endometriosis. This focus on emotions and feelings indicated another acknowledgement of users as thinking, feeling people, but presented a tension with the rest of the app's endorsement of biomedical understandings of endometriosis as a physical disease. This tension suggests that app developers may have been aware that women desire a more holistic approach to understanding their endometriosis (Seear, 2014) but considered this to be constrained by the nature of biomedical knowledge and intervention approaches. Given that medical professionals tend to value quantitative evidence of endometriosis severity rather than 'subjective' reports from women (Denny & Weckesser, 2020), Flutter's self-tracking may have been an attempt to offer women more credibility within biomedical encounters. In this way, Flutter positioned users as empowered by the app's data collection and visualisation to communicate their experiences to doctors more effectively and receive better health care.

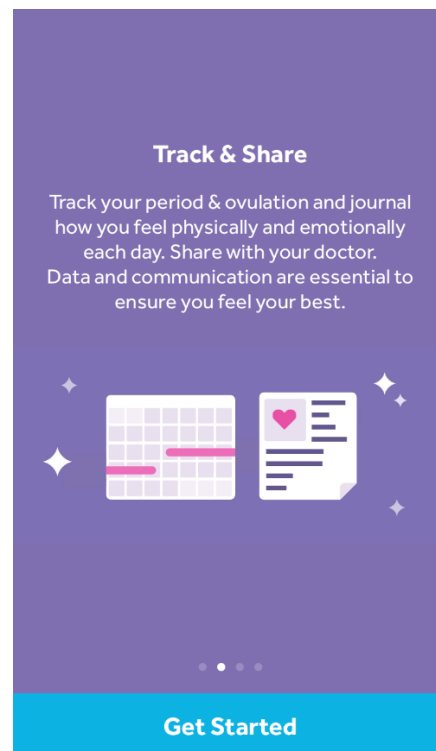


Figure 15. Screenshot of "Track & Share" screen in pre-registration stage of Flutter.

Reproduced with permission.

Finally, Phendo constructed collecting data about endometriosis through daily tracking as an essential method of contributing to scientific research on endometriosis. Phendo constructed quantitative data as critical to understanding endometriosis and described their work as a “participatory approach to understanding endometriosis through citizen science”. Using the phrase ‘citizen science’ used neoliberal discourses of ideal citizenship to construct citizens as ideally willing to share their data to improve their own health and the health of others (Lupton, 2017). Therefore, this offered app users the subject position of responsible citizens who engage in intense self-tracking to support science. While Phendo acknowledged that self-tracking may be uncomfortable or inconvenient as part of the informed consent procedure and provided options for users to reduce or stop tracking at any time, they also strongly encouraged continued tracking through “Citizen Endo challenges” and frequent reminders that “the more you track, the more we all learn about endometriosis”.

This may reflect dominant constructions of femininity, where women prioritise the needs of others over their own discomfort or distress (McRobbie, 2009).

5.5 Summary

In this chapter, I used evidence from apps to demonstrate how both biomedical and natural wellness apps drew on a discourse of women's bodies and behaviours as confusing to construct endometriosis as confusing in ways that maintained their respective claims to knowledge. Both types of app positioned women with endometriosis as having confusing bodies, and as having less knowledge (i.e. being more confused) about endometriosis than medical or natural health professionals. The MCDA I conducted showed that apps also constructed endometriosis as all-encompassing to position women with endometriosis as experiencing daily physical and emotional distress. Finally, my analysis demonstrated that both constructions worked together to motivate women with endometriosis to use the apps to track their physical, emotional and behavioural experiences to generate a set of accurate, quantifiable data that could be meaningfully interpreted by experts and app algorithms. Apps positioned users as responsible for self-tracking to solve the distressing puzzle of their endometriosis for themselves, doctors and to support scientific progress. Moreover, these self-tracking functionalities positioned users as unable to interpret their embodied experiences of endometriosis unless they engaged in self-tracking. Although women were offered a more knowledgeable subject position if they engaged in self-tracking, this empowerment was limited: women's experiential knowledge was only constructed as legitimate due to algorithmic and expert interpretations.

6 ‘Controlling’ Endometriosis: Creating Healthy, Feminine, Neoliberal Subjects

In this chapter, I build upon Chapters 4 and 5 by showing how apps discursively constructed self-tracking as a way for users to identify ‘problematic’ health or lifestyle behaviours contributing to or causing their endometriosis. Using colours, images, textual context and self-tracking affordances, apps constructed endometriosis as something that users should manage and control through behavioural and lifestyle changes. Moreover, this analysis showed that apps aligned their treatment recommendations with dominant neoliberal, healthist and postfeminist discourses about women’s health (Riley et al., 2018).

6.1 Self-managing endometriosis through medicine, behaviour and nutrition

Apps recommended a wide range of behaviours and strategies that users could undertake to manage or control endometriosis. Some recommendations required the involvement of people other than the user, such as biomedical options (i.e. surgeons performing laparoscopic surgery and doctors prescribing hormone therapy). More commonly, apps encouraged users to undertake behaviours and lifestyle changes themselves, commonly described as ‘self-management’. Some recommendations emphasised changing the physical endometriosis or dysfunctional hormones, while others focused on changing the user’s thoughts and feelings related to their endometriosis experience. In this section, I analyse how apps used language and aesthetic choices that drew heavily on neoliberal ideals of citizenship to construct users as autonomous individuals who were willing and able to learn about available options and choose the responsible course of action to control their endometriosis.

6.1.1 Medical interventions.

Apps with a biomedical orientation constructed interventions that acted upon the physiology of endometriosis as more effective than interventions that did not, reflecting biomedical constructions of endometriosis as a biological, physical disease. This is seen in

Flutter's list of available treatment options (shown in Figure 16), which recommended 17 treatment "options" across four main treatment categories: Self Treatment, Hormones, Surgical Procedures (laparoscopic), and Other Treatments (comprised of synthetic hormone treatments). Nearly all these treatment options (except for self-treatment options) involved users undergoing surgery or taking hormonal therapy to reduce or remove endometriosis from the body. Flutter's endorsement of biomedical interventions was further reinforced by the description of laparoscopic excision surgery as "the only option that has the potential to fully remove endometriosis", which constructed complete removal of endometriosis from the physical body as the only way to fully control endometriosis. Therefore, Flutter's treatment recommendations reinforced biomedical constructions of medical professionals as knowledgeable experts who can control endometriosis by physically entering and modifying the material body (Young et al., 2018).

In contrast, Flutter constructed self-treatment options as the least valid and effective. Users were offered only two 'self-treatment' options: a heating pad, and the statement "Some women endorse an anti-inflammatory diet to relieve pain". By using the approximate and less authoritative phrase "some women endorse", Flutter implied that not all women find the anti-inflammatory diet helpful. This vagueness functioned to question whether women's 'endorsements' are valid and reinforced the notion that women's perspectives are not expert or authoritative (Machin & Mayr, 2012). No other treatment option was qualified in this way, indicating that Flutter considered an anti-inflammatory diet to be a less valid option than biomedical interventions. Despite this, other parts of Flutter strongly encouraged users to follow the anti-inflammatory, anti-oestrogen "Endo Diet" even if it did not help endometriosis symptoms (discussed later in the chapter). These contradictory suggestions revealed tensions between Flutter's reproduction of biomedical discourses, positioning medical professionals as the agents controlling endometriosis by reducing or removing it, and

neoliberal discourses, positioning citizens as responsible for doing anything they can to manage their health, even when medical knowledge does not consider it particularly helpful.

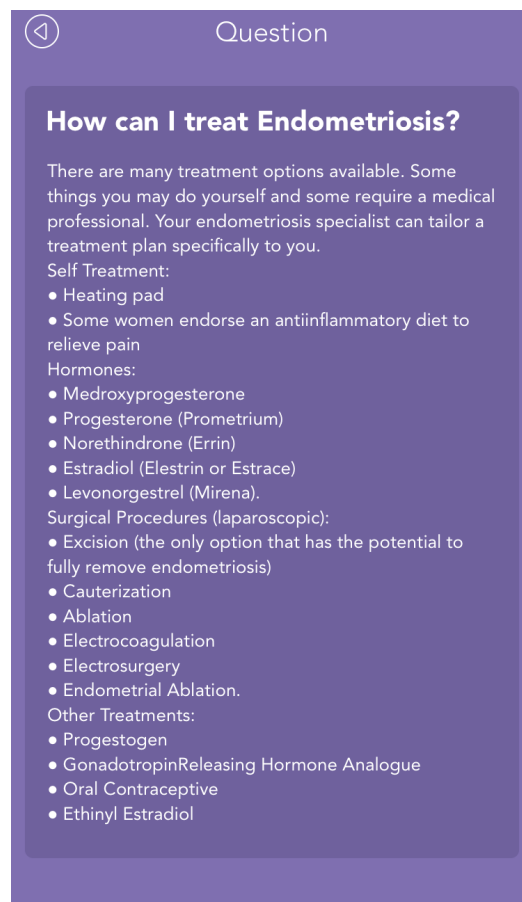


Figure 16. Screenshot from "How can I treat Endometriosis?" section of Flutter.

Neoliberal and healthist discourses were also reflected in Flutter's construction of users as responsible for learning about endometriosis treatment options and making rational choices based on this knowledge. The list of available treatments was titled "How can I treat endometriosis?", which positioned the user as the agent leading their endometriosis treatment. However, Flutter listed surgical and hormonal treatment options using highly medical language (i.e. generic and brand names for pharmaceutical drugs) with no additional information offered about what the treatment involved or how to decide between them, making the list unhelpful to anyone without expert biomedical knowledge about endometriosis. Therefore, these discursive choices worked together to position users (as

agents making their treatment decisions) as responsible for conducting further research into each treatment option. Flutter appeared to assume that users had sought (or would seek) this additional knowledge from an “endometriosis specialist” and constructed these specialists as able to provide the required knowledge to tailor an endometriosis treatment plan for the user. Taken together, Flutter positioned users as health care consumers responsible for becoming knowledgeable about and taking control of their treatment, on the clear condition that treatment decisions involve medicine and medical professionals.

Similarly, Endo Diary developed a ‘Mini Game’ that incorporated visual and linguistic metaphors into the game design to construct users as responsible for controlling endometriosis. Upon entering the mini game, users were presented with a pink, cartoon ‘pet’ uterus that was sad and crying (see Figure 17.a). The uterus hovered above a glowing pedestal in a wild garden under a starry night sky, reinforcing previously discussed social constructions of the female reproductive system as part of the dark, mysterious and strange parts of nature. The game instructions encouraged users to “keep [their] pet happy” by “clearing” the blood drop to the left of the uterus by pressing a purple pill button at the base of the screen (see Figure 17.b). Pressing the pill button caused the blood to disappear and the pet uterus to begin smiling (see Figure 17.c). The game was reset, and users were required to repeat the process daily.

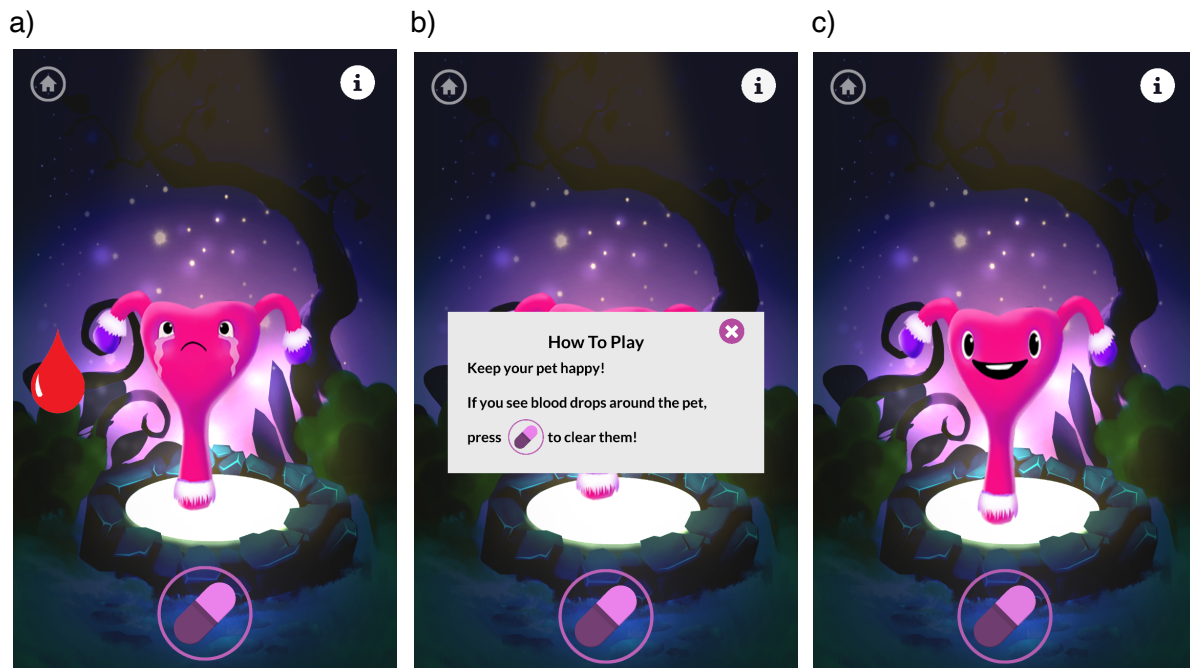


Figure 17. Three screenshots from the Mini Game of Endo Diary. Reproduced with permission.

The game's design reinforced that endometriosis is an all-encompassing disease of the female reproductive body caused by 'out-of-control' hormones (Jones, 2015). It also reproduced historical biomedical discourses that women are controlled by their uterus by constructing women as taking pharmaceutical hormonal medication to keep their uterus happy (Jones, 2015). Third, the game constructed endometriosis as something that can only be controlled temporarily through repetitive and ongoing interventions, rather than something that can be permanently resolved. Together, these constructions offered women with endometriosis a subject position of being in control of their unruly reproductive bodies, but only if they continued taking hormonal medication long-term. However, as ongoing access to hormonal medication is controlled by biomedical professionals (who prescribe and monitor whether medication is effective), the game ultimately reinforced that medical professionals are more knowledgeable and in control than women, but that women remain responsible for their participation in controlling endometriosis.

Moreover, it is important to acknowledge that Endo Diary is an app developed by the Singapore branch of the pharmaceutical company Bayer for a Singaporean audience. Therefore, any analytic insights must consider the function of ‘cute culture’ in mobile technologies across Asia. Hjorth (2007) cautioned against ethnocentric Western readings of Asian cute culture as infantilising, feminine or childish, pointing out that ‘cute’ cartoon aesthetics like Endo Diary’s ‘pet’ uterus have long been used by people of different ages and genders as a way to humanise and socialise cold technological spaces. Therefore, the ‘pet’ uterus may be better understood as a way for Bayer to encourage Singaporean women to feel comfortable and safe enough to a) use an app offering information and tracking of endometriosis and b) use pharmaceutical hormonal therapy as a treatment for endometriosis.

6.1.2 Self-management behaviours.

Apps also recommended that users manage their endometriosis using strategies that did not require approval from a biomedical professional, which they typically described as ‘self-treatment’ or ‘self-management’. Apps suggested a vast range of self-management behaviours related to nutrition, exercise, and lifestyle. Compared to biomedical options, apps constructed self-management recommendations as able to control symptoms of endometriosis, rather than the endometriosis itself. Self-management recommendations often aimed to alleviate pain, gastro-intestinal problems, mood problems and low energy levels.

Self-management recommendations invariably drew upon neoliberal models of citizenship to construct users as active and individualistic participants responsible for managing their endometriosis well. Even Phendo, which avoided making treatment recommendations, constructed approaches to self-management as always highly individualised. Figure 18 shows one of Phendo’s central tracking questions, “What did you do to self-manage?”. Users were able to choose from a list of fourteen “self-management”

behaviours, consumer goods and services that they had used that day, or to select that they had performed ‘None’ of the options listed. All options acted upon the material or mental experience of the individual person, drawing on constructions of endometriosis as located within the body. Related to this, nearly all the behaviours could be performed alone: only massage, physical therapy, and talk therapy potentially required input from another person. This reinforced constructions of managing endometriosis as an individual pursuit.

Phendo’s question also constructed some behaviours as ‘self-management’ and excluded others. Users could only choose a small range of ‘self-management’ behaviours and could not add and track behaviours not included on the list. The brevity of the list combined with Phendo’s typical scientific aesthetic (as previously discussed) communicated that behaviours to manage endometriosis at home are only self-management if they are supported by scientific evidence. This is supported by evidence that all the listed options have been shown by survey research with women in Australia to be ‘good’ self-management options, in that they are effective at symptom reduction, cause minimal adverse effects, or both (Armour et al., 2019). Consequently, Phendo constructed behaviours that were not available for users to select as something other than self-management. This potentially offered users who performed behaviours on the list the subject position of self-managing endometriosis correctly, and users who did something else as managing endometriosis ‘incorrectly’. However, the discursive construction of these behaviours as evidence-based is somewhat contradicted by Phendo’s stated purpose: it aims to collect evidence about users’ endometriosis symptoms and management to “better understand endometriosis”, suggesting that not enough is currently known about what constitutes effective self-management.

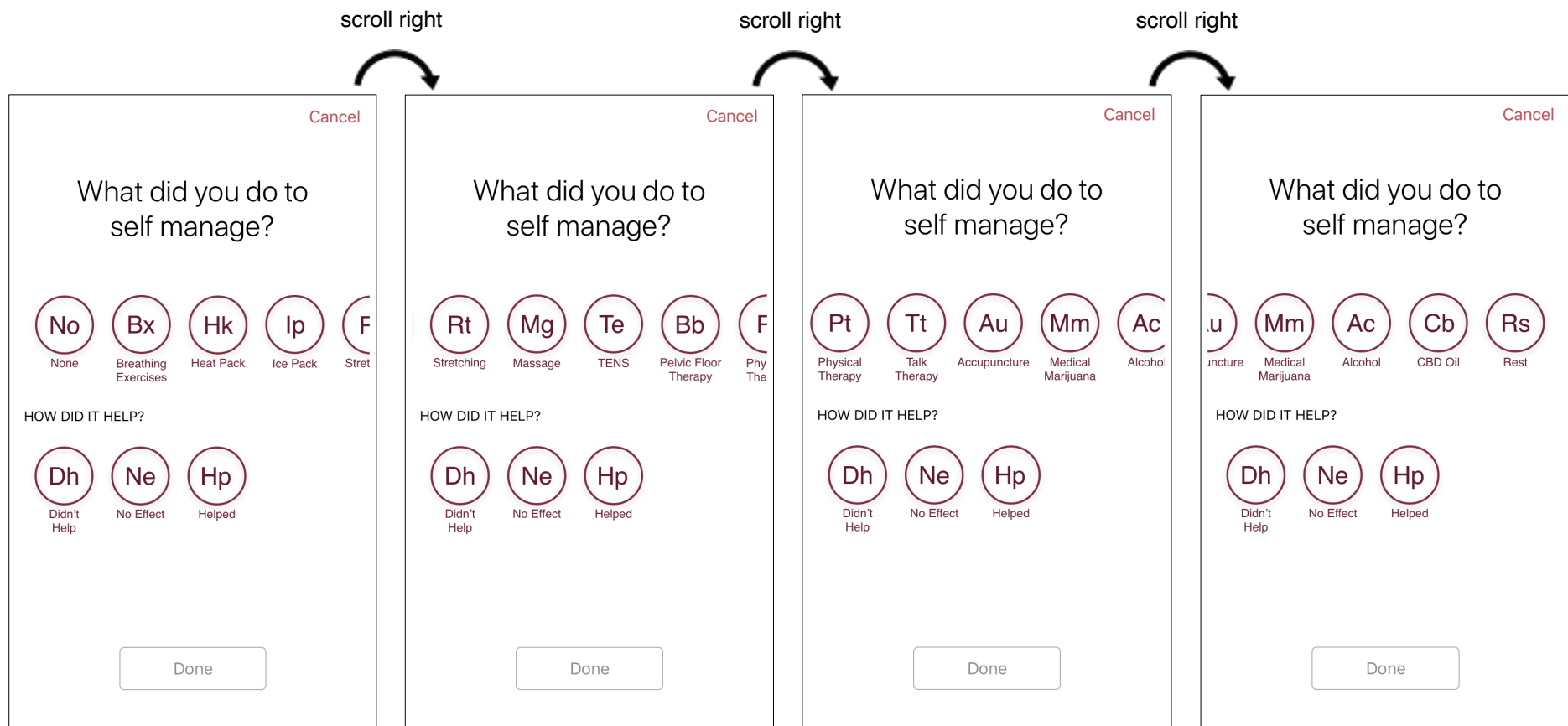


Figure 18. Four partial screenshots from the "What did you do to self manage?" question of "Track this Day" feature of Phendo. The question allowed users to select from 15 self-management behaviours and three answers to whether the selected behaviours helped. Users were able to scroll right to access all options. Reproduced with permission.

CONTROLLING THE MONSTER: ENDOMETRIOSIS APPS

Although Phendo's self-management behaviours were presented as options users can freely choose or not choose, other discursive strategies constructed users as responsible for choosing to undertake them. First, the open-ended question "What did you do to self-manage?" rather than a more closed 'Did you do...' positioned the ideal, default behaviour to be one of assessing, monitoring and managing the 'self' (Johnson, 2014). In the context of using the app, the self-management question immediately followed a question asking users to rate their day using options ranging from 'great' to 'unbearable'. As a result, users who rated their day on the lower end of the spectrum were immediately offered self-management as a solution for pain and distress. Second, users were asked to track whether the selected interventions 'Didn't Help', had "No Effect" or 'Helped', positioning these behaviours as able to make a difference to the person's negative symptoms, and therefore worth undertaking. Notably, users could only track whether interventions helped overall and could not track the efficacy of individual behaviours. Although Phendo marketed self-tracking as a way for users to "gain potential insights" into their health, this blunt measurement limited users' ability to reflect about their behaviours and experiences in nuanced ways. It also precluded researchers from undertaking fine-grained analysis into the effects of individual strategies on endometriosis symptoms. Finally, options varied in terms of accessibility and cost, which may encourage users to attempt at least some of the options. By constructing self-management as an obvious and responsible choice, Phendo positioned users who experienced endometriosis-related distress and chose to not to do self-management as irresponsible.

6.1.3 Nutritional interventions.

Apps regularly recommended that users add foods and supplements containing 'anti-inflammatory' compounds and various nutrients (i.e. minerals, vitamins, antioxidants) to their diet. These recommendations drew on nutritional science discourses that construct properties of food as able to affect the material body when consumed in ways that can both improve and

worsen endometriosis symptoms (Dodds & Chamberlain, 2017). These recommendations also reflected neoliberal and consumerist discourses by constructing consumer choices about food and supplements as a primary means for users to manage their health. Often, apps offered vague or limited explanations for how particular consumption behaviours specifically acted upon endometriosis symptoms. For example, Endo Empowered used non-specific language to recommend that users buy and drink a variety of teas that can “aid the body on so many levels” and “support your body on different levels from boosting immune function to reducing period pain and endometriosis”. This vagueness constructed users’ food consumption choices as a central and obvious part of managing endometriosis, and also illustrated how many app recommendations drew on broader healthist discourses that people should always seek to improve their health beyond addressing endometriosis symptoms (discussed further in the next section).

Apps also encouraged removing foods constructed as posing an increased risk of causing or exacerbating endometriosis. Commonly, apps often recommended that users eat in ways that reduced ‘abnormal’ or ‘excess’ levels of the hormone estrogen, reflecting biomedical constructions of endometriosis as an estrogen-dependent disease. The most explicit explanation for targeting estrogen was seen in an article republished (without appropriate acknowledgement) by Flutter, called “The Endo Diet – Part 1” (Chin, 2019). As shown in the following extract, Chin described the ‘Endo Diet’ as a way to reduce estrogen and manage the risk of experiencing increased endometriosis symptoms:

The basic idea is that endometriosis is fuelled by estrogen. In our modern world, where genetically modified organisms (GMOs) and uber-processed foods abound, external sources of estrogens can be found almost everywhere you look. We have all heard about the risks associated with BPA-containing plastics and GMOs, but what about the foods we already consider healthy? Many different chemicals and even

natural foods contain properties that create excess estrogens, or compounds that mimic estrogen. Not only are you fuelling your body while eating a seemingly healthy snack of soybeans, you might unwittingly be fuelling your worst enemy: endometriosis.

In this extract, Chin drew on popular health and nutrition discourses of ‘good’ and ‘bad’ foods to construct estrogen as always ‘unhealthy’, even when it exists in foods typically thought of as ‘healthy’ (such as vegetables like soybeans). She also drew upon discourses of risk to construct unhealthy foods as harmful and pervasive threats, due to modern food production techniques like genetic modification and “uber-processing”. The high risk posed by modern, estrogen-increasing food was reinforced by Chin’s discursive separation of “chemicals” from “natural foods”, constructing natural chemicals as healthier than synthetically produced chemicals, unless they create estrogen or estrogen-like compounds.

Therefore, the risk of consuming estrogen that directly “fuels” endometriosis provided the rationale for encouraging users to remove all foods that may be implicated, as shown in the extract from next section of the article:

I began with a daunting step: a one-month complete detox. I went on a strict gluten, soy, dairy, sugar, chocolate, caffeine, and alcohol-free regimen. On top of that, I began eating only organic foods. It sounds far worse than it really is.

By using the word “detox”, Chin constructed unhealthy foods containing estrogen or estrogen-like compounds as toxins poisoning her body. This legitimised her decision to eliminate not only types of food (e.g. dairy) and compounds found in food (e.g. gluten) but also food processed in ways perceived as risky or unhealthy, such as non-organic farming. She described this as “strict” and “daunting”, but subsequently stated that “it sounds far worse than it really is”. These contradictory assertions appeared to reflect that Chin

constructed managing endometriosis through dietary consumer choices as difficult but necessary, given how bad endometriosis is. For example, Chin acknowledged the time, learning and effort required to adhere to the risk-reducing, restrictive diet when she stated:

The bulk of my food is fresh, organic, or locally grown fruits and veggies. I like to talk to the local farms about their use of pesticides and make my decisions to buy non-organic based on their farming techniques. To be honest, it is HARD to find quality, fresh, and affordable organic food, so I have a few local places I feel comfortable buying from, even though they aren't certified organic farmers. I wash those fruits and veggies thoroughly. Any meat that I buy, however, I make sure is organic, and if possible, grass-fed. Chicken is especially important, because of added growth hormones.

In this extract, Chin constructed a wide range of foods as posing an increased risk “fuelling” her endometriosis: non-fresh food, food grown with pesticides, food not grown locally, and meat from animals fed with growth hormones and/or with something other than grass. This opened up a complex range of consumer choices about what food to buy as the only way to manage this risk, again reflecting neoliberal and healthist discourses that consumption choices are central to being healthy. Chin exhibited the expert knowledge about agricultural and farming techniques required to make informed consumer choices, and the time and effort required to identify and mitigate the risks associated with non-organic food. Although Chin used capitalisation to emphasise how “HARD” it is to find affordable food that complies with the restrictions of the Endo Diet, she only considered this as an issue for individual consumers rather than as a political or structural issue. Furthermore, this was the only reference across all the apps to the high financial or time cost of maintaining such a diet. Therefore, Chin’s article positioned women with endometriosis as not only responsible for

eating in ways that reduce their risk of increasing estrogen, but also responsible for educating themselves about how to do this and finding ways to achieve it, despite significant difficulty.

6.2 Self-managing endometriosis is essential for being ‘healthy’

Self-management recommendations did not only focus on controlling endometriosis or endometriosis symptoms; apps also commonly recommended that users try to improve their overall ‘health’ and ‘wellness’ as well as improving their endometriosis. Apps often justified focusing on overall health by arguing that endometriosis is both more prevalent and more severe in people who have poorer levels of health, thereby positioning people with endometriosis as unhealthy. Therefore, apps recommended that users should improve their health by assessing and modifying many aspects of their daily lives, regardless of whether these changed endometriosis symptoms or not. As with the endometriosis-specific recommendations, apps commonly recommended general nutrition and exercise recommendations, but also encouraged users to do generally ‘healthy’ things like sleep more, use breathing exercises to breathe more deeply, and improve their mental health. The following extract from Endo Empowered demonstrates how apps constructed successful endometriosis management as synonymous with achieving ‘wellness’:

We are going to begin our path to wellness by changing what we say to ourselves each and every day. Each morning, you are now going to say this phrase to yourself: “What can I do right now to feel better?” This is about doing things that are within our reach and provide our bodies with whatever tools we can. It is about making a choice of putting ourselves and our health first. Every decision you make, everything you think, eat, drink and do for your body will have an impact on how you feel.

The metaphor of a ‘path to wellness’ enacted a journey narrative, in which people with endometriosis are travelling from a state of sickness to one of wellness. This journey

metaphor was visually reinforced by Endo Empowered's logo (a dandelion pappus) and Flutter's logo (a butterfly), as both can symbolise freedom, flight and movement to new places (discussed in Chapter 4). This offered users a subject position of being sick and unhealthy, and incentivised users who accept this position to focus on improving their health to become healthy. The extract drew heavily on neoliberal ideals of people as autonomous individuals who take active responsibility for their health by constructing health and wellness (and shifting from an unwell position) as the primary goal in user's lives. Turner (the owner of Endo Empowered) framed health behaviours as a "choice of putting ourselves and our health first", although it was not clear what (or who) in the user's life should be positioned as less important than achieving health. 'Putting one's health first' also required users to consider how every thought, meal, and behaviour might improve or reduce their health and wellbeing. Alongside this all-encompassing requirement, Turner constructed managing endometriosis as easy by using collective pronouns like 'we' and 'our' to connect with the user, as if they are embarking upon the same journey together. The extract also emphasised "doing things that are within our reach" to imply that managing endometriosis does not require excessive effort or cost. These apparently contradictory constructions reflect that while Endo Empowered constructed endometriosis as all-encompassing, it also endorsed neoliberal discourses to construct people as able to make healthy choices.

Similar to the daily hormonal therapy proposed by Endo Diary, Endo Empowered's extract constructed endometriosis as something that can only be controlled through repeated daily intervention. However, Endo Empowered constructed health and wellness as acting upon "how you feel" physically and mentally each day, rather than on endometriosis specifically. This contrasted with other language in Endo Empowered that constructed endometriosis as able to be permanently 'fixed' and 'cured' (discussed in Chapter 4). These opposing concepts communicated that people with endometriosis can successfully resolve

their negative experiences of endometriosis regardless of whether endometriosis itself is physically removed. This potentially offered users an agentic, empowered subject position, as they are not reliant on biomedical practitioners to be the gatekeepers of whether they receive relief or treatment. However, the implication of taking up such a position is that users become responsible for managing an ever-present risk of increased endometriosis symptoms. If people can manage their endometriosis experience by undertaking enough behavioural change, those who still experience negative endometriosis symptoms or distress are positioned as both unhealthy and as failures for not doing enough.

In some cases, apps encouraged users to focus on overall health while explicitly acknowledging there was limited evidence that doing so would improve endometriosis. Figure 19 shows two screenshots from an article Flutter republished (without appropriate acknowledgement) called “Endometriosis: Nutrition and Exercise” that encouraged “girls” with endometriosis to make changes to their diet (Center for Young Women's Health, 2017). The article used a question and answer format; questions used a first-person perspective (i.e. “How can I make sure...”) and were written in pink. This constructed the person asking the questions as the young woman with endometriosis targeted by the article, and again positioned users as agents responsible for managing their health alongside taking medication. The answers were written in informative and plain black text, which positioned the article author/s as experts informing the young woman. Despite positioning themselves as experts on endometriosis-related health, the article author/s primarily offered general health information in place of endometriosis-specific information and acknowledged that there was “very little research done” on how diet and exercise affected endometriosis.

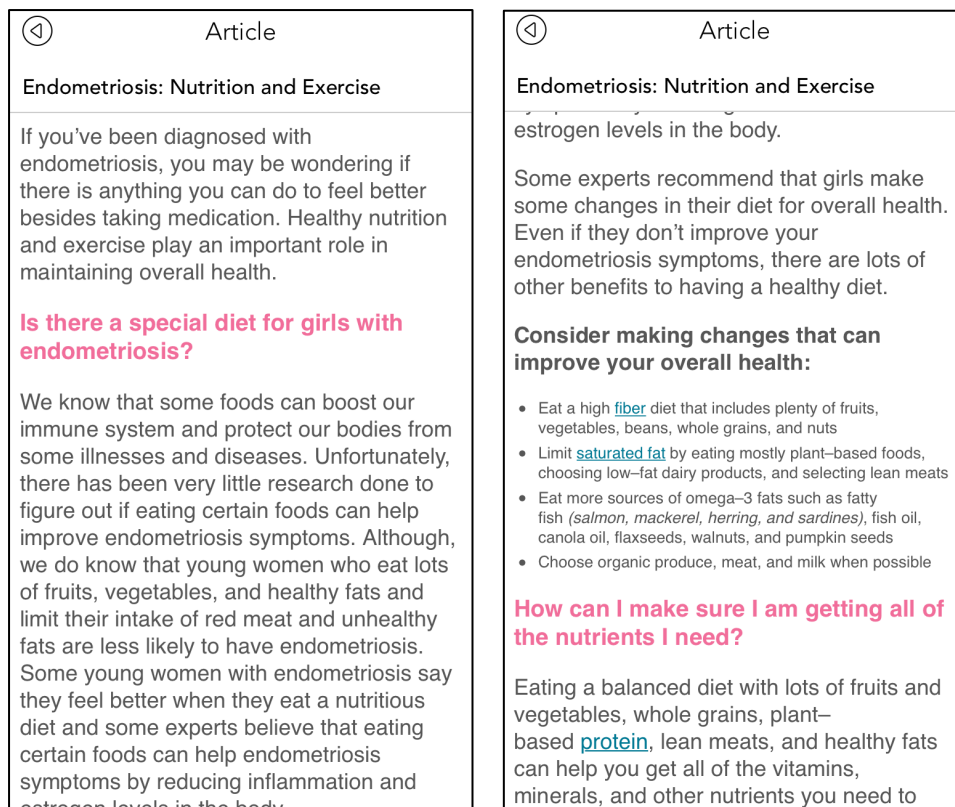


Figure 19. Two partial screenshots from the "Endometriosis: Nutrition and Exercise" article republished in Flutter. Reproduced with permission.

As in the example from Endo Empowered, the author/s constructed improved nutrition and exercise behaviours as helping users to indirectly improve endometriosis by “feeling better” and maintaining “overall health”. As in previously discussed examples, the author/s drew on general nutritional discourses that argue there is scientific evidence that particular foods act on the body (e.g. “some foods boost our immune system”). The article described healthy eating similarly to other apps, such as eating unprocessed foods, avoiding plant estrogens and eating organically. They also used hedging language to describe the source of these claims, such as “some experts” and “some young women”. This functioned to maintain the credibility of their hypotheses and claims without requiring them to provide concrete evidence for them. Although the author/s acknowledged that very little is known about how foods materially affect endometriosis, they drew on healthist discourses to argue

that girls with endometriosis should engage in healthy eating and exercise behaviours due to the “other benefits” offered by doing so. Nonetheless, the author acknowledged that dietary changes may not affect the young person’s experience of endometriosis-related pain or distress. Altogether, the author/s continued focus on healthy eating despite the limited evidence constructed nutrition and exercise behaviours as a more important part of health than goals like pain management or subjective wellbeing. This example also illustrated a tension seen throughout the apps between competing ideas of what ‘health’ is. Apps attempted to support users to achieve ‘health’ by reducing or resolving their endometriosis symptoms, while simultaneously relying on neoliberal discourses to construct health as achieved by continuously performing ‘healthy’ behaviours and consumption choices, regardless of whether they alleviate symptoms.

Finally, this article demonstrated how apps also conflated normative beauty ideals with health. Later in the article [not shown in screenshots], the author/s encouraged users to undertake exercise to “help [users] maintain a healthy weight and give [them] energy”. This recommendation constructed having a low body weight as a marker of good health, and as an important part of controlling endometriosis. This reflects how apps often constructed weight management as equally or more important than reducing endometriosis-related illness or distress, which encouraged young women to discipline their bodies in ways that were less about improving their wellbeing and more about complying with social expectations for healthy, feminine bodies. I discuss this in more detail in the next section.

6.3 Becoming a ‘healthy’ woman with endometriosis

Apps drew on dominant discourses about women and femininity to construct ideal self-management behaviours and practices outlined in the previous sections in highly gendered ways. Apps used imagery and language to construct gendered norms and practices

like returning to 'nature' and caring for the body as essential for women with endometriosis seeking to achieve a healthy subject position. These recommendations and associated subject positions drew on conceptions of both traditional femininity and neoliberal femininity, and again produced individual consumer choices as the main mechanism for users to perform these feminine practices and behaviours.

6.3.1 Healthy women as 'natural'.

Apps used colours and images associated with a) nature and b) femininity to produce femininity and nature as linked. When combined with images connoting health, these worked to construct achieving health as a natural and essential practice for women with endometriosis. For example, the Pain Management feature of Flutter (see Figure 20) demonstrates how apps commonly imagined healthy women (i.e. women successfully managing endometriosis) and healthy behaviours. The feature included links to mostly externally produced videos with titles like 'Menstruation Meditation', '5 Tips for Stress Management', and 'One Minute Meditation for Endometriosis'. The emphasis on meditation and managing stress not only reinforced that endometriosis (and menstruation) is stressful but also drew on psychological discourses of using mindfulness to cope with pain (Davis, Zautra, Wolf, Tennen & Yeung, 2015) and postfeminist constructions of women's psychological states as always flawed but modifiable (Gill, 2007; Riley et al., 2019).

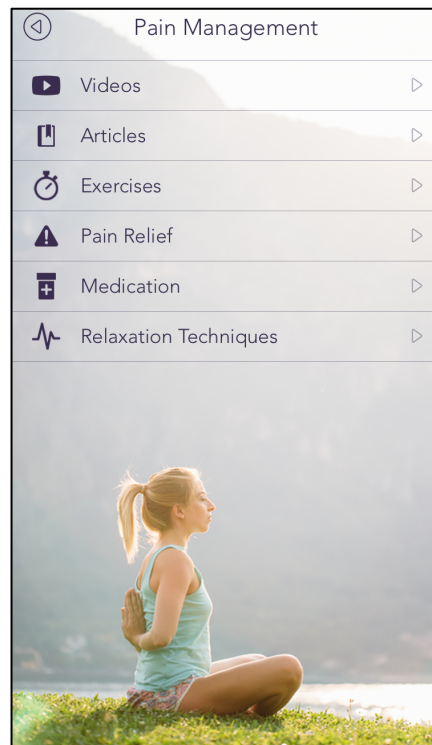


Figure 20. The “Pain Management” feature of Flutter. The subheadings Exercise, Pain Relief, Medication and Relaxation Techniques functioned as tags for the videos and articles; the videos and articles often fit under multiple subheadings. Reproduced with permission.

The accompanying image depicted a woman sitting on the grass outside surrounded by water and hills while she calmly performed a yoga pose. The woman’s face was partially obscured, and the background was unfocused, reflecting that the image was not intended to depict a specific person or event but to symbolise successful pain management (Machin & Mayr, 2012). However, using a White, thin, toned, young and clear-skinned woman as a symbol of health conflated health with Western beauty ideals and positioned women who do not meet these standards as unhealthy and non-normative (Doshi, 2018; Riley et al., 2018). The warm, bright lighting of the image connoted positivity and optimism, while the outdoor, natural setting drew on Western dualistic binaries that associate nature with femininity, fertility, passivity and balance (Butler, 1999; Wardman et al., 2012). The image constructed healthy performances of womanhood with spirituality (through the practice of yoga) and

nature, which offered users what Doshi (2018) called an “Earth goddess” subject position. Doshi argued that women’s health apps commonly position healthy women as “Earth goddesses” in ways that glorify middle-class, White motherhood over other expressions of womanhood. Indeed, the Pain Management feature only promoted gentle, calm activities such as meditation, Pilates and yoga. As well as encouraging women to manage their thoughts and feelings, popular approaches to Pilates and yoga in Western countries are often part of gendered fitness practices that focus on producing thin, toned and feminized bodies that comply with dominant (White, middle-class) body aesthetics (Lloyd, 1996; Markula, 2008).

Other apps also idealised practices and subjects aligned with ‘natural’ femininity. Figure 21 shows Endo Empowered’s “Daily Action Steps Poster”. The poster heading was “Daily Action Steps” in blue cursive font, which sat above 15 stock images representing different daily recommendations. Endo Empowered advised users to print the poster, place it in a prominent place and each day, cross off each Action Step they “achieved”, which constructed health and wellness as significant daily priority and as a highly individualised pursuit. The poster also discursively produced health as synonymous with the ‘natural’. The stock images depicted nature scenes of golden sand beaches with gentle ocean waves, green forests, ocean vistas, and grassy areas. One set of images represented the app’s daily recommendation to “make green [food] a part of your life” and depicted raw fruit and vegetables (an apple, a juice and an avocado salad). Another image depicted flowers scattered next to a bowl of coloured pills, which represented the recommendation for users to incorporate natural supplements into their diet. The colour scheme of the images was predominantly green, blue, white and light peach (the White skin tone of the subjects, discussed next), which was reinforced by primarily blue, white and pink font. All images were warmly lit and in soft focus, making the images look dreamy and inviting (Kress & van Leeuwen, 2006). The choice of images and colours constructed nature as calm, clean and

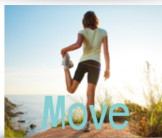
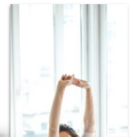
good; this kind of nature is symbolically associated with broader concepts like vitality, beauty and calm. Therefore, Endo Empowered's use of such images discursively linked these same concepts with performing health and wellness behaviours.

Moreover, the subjects depicted in the poster constructed the healthy female subject as White, young, thin and beautiful. All depicted subjects were White women performing a variety of actions alone: exercising, stretching, meditating, journaling, sleeping, and walking on the sand. These images of women were used to symbolise wellness rather than depicting individual, specific women; this was achieved by using saturated colours, soft focus, cropped body parts (such as the feet walking on sand) and a lack of naturalistic details from actual daily life (Kress & van Leeuwen, 2006). The images also communicated that the pursuit of health is highly individualistic, as only one stock image (of three women doing peace signs while smiling down at the camera) showed more than one individual. Subjects performed a particular type of natural, traditional femininity that conflated idealised notions of external beauty and grace with inner goodness and virtue (Wardman et al., 2013), seen in the way that subjects were depicted wearing subtle make-up and hairstyles, rather than the heavier styles associated with more sexualised, empowered performances of femininity (Elias, Gill & Scharff, 2017; McRobbie, 2009). Most of the subjects were smiling, constructing the healthy, feminine subject as content and peaceful. Together, these images highlighted how Endo Empowered drew on dominant discourses of femininity that conflate feeling good with looking good (Elias et al., 2017) and produced traditional femininity (i.e. embodying beauty, health and docility) as a natural and desirable pursuit for women with endometriosis.

Daily Action Steps

within my 21 Day Endo Wellness Challenge

As you go through the 21 Day Challenge, you will slowly add more things to your day



Find out more about managing Endometriosis effectively: www.endoempowered.com

Figure 21. The “Daily Action Steps Poster” available for download through the Endo Empowered app. Users were encouraged to print out the poster in full colour, laminate it, place it in a prominent place and cross off completed ‘Action Steps’. Reproduced with permission.

6.3.2 Healthy women as living in line with their natural biology.


As discussed in Chapter 4, apps constructed endometriosis as a disease of the female reproductive body caused by hormonal imbalance. Some apps extended their symbolic association between women and nature to discursively produce women with endometriosis as living in ways that stopped their reproductive bodies from functioning ‘naturally’ and ‘normally’. In particular, apps drawing on natural, wellness discourses implicated modern, unnatural ways of living and eating as negatively affecting natural hormonal levels. As a result, these apps encouraged women to change their lifestyles to support their natural biological functioning. Advice about living more naturally often drew on biologically essentialist discourses about balancing female sex hormones, which obscured that apps often reflected social constructions of appropriate behaviour for women.

For example, Figure 22 depicts a partial screenshot of an email sent by MyFLO developer Alisa Vitti (personal communication, June 28, 2019) advertising an online live event for users to receive Vitti’s advice about achieving “hormonal healing” of their “rotten period problems”.² Vitti’s use of the words “healing” and “rotten” metaphorically constructed imbalanced hormones as a decaying wound, injury or sickness caused by the user’s behaviours and lifestyle choices. The accompanying image depicted Vitti wearing a pink top and smiling while sitting in a light, airy white room next to pot plants. Vitti made direct eye contact with the viewer, which created a sense of connection in the same way that Turner used collective pronouns (Machin & Mayr, 2012). Two Flo Living products were positioned in front of the pot plants, clearly advertising them as solutions. One product was Vitti’s pink book called *Woman Code*, which constructed women as having bodies and

² While this email did not specifically include endometriosis, endometriosis is frequently referred to as one of these period problems in other emails and in the app.

hormones so confusing that they need to use a code to decipher them. The other product was a set of white pill bottles with coloured labels; they were visibly the ‘Balance by FLO Monthly Supplement Kit’ advertised elsewhere in the app as a way to normalise female hormonal functioning. This image produced Vitti not only as having the knowledge and products required to teach users to heal themselves, but her thin, feminine body shape, natural make-up and hair style, happy smile and clean, airy, natural setting all constructed successful living as aligned with ideals of natural (White) femininity.

The emphasis on living in line with the requirements of female biology was powerfully reinforced by the capitalised email heading “STOP LIVING LIKE A MAN (...AND GET THE BODY, CAREER AND LIFE YOU WANT!)”. This statement constructed users as living ‘like men’, which precluded them from achieving their body work goals, career goals and life goals in general. Living ‘like a man’ was constructed as ignoring how different hormone patterns throughout the menstrual cycle differentially shaped female brains, bodies, and energy levels. In this way, cisgender women were produced needing to change their health behaviours throughout the month to accommodate their biological needs to avoid hormonal sickness or injury, while cisgender men (who do not experience menstrual cycles) were able to perform the same health behaviours without limitation.



STOP LIVING LIKE A MAN (...AND GET THE BODY, CAREER, AND LIFE YOU WANT!)

TODAY, FB LIVE @ 1 PM EASTERN

Hormonal timing is everything when it comes to hormonal healing—and solving rotten period problems like PMS, bloating, acne, migraines, and heavy or irregular periods.

You can eat all the right foods and get enough exercise, but if you're not paying attention to **WHEN** you eat specific foods and how your exercise changes throughout your cycle, you won't get results.

The FLO Protocol helps women solve period problems, improve overall health, and revolutionize their personal and professional lives because we teach women not just what to eat and how to move, but **WHEN** to do it.

Join me for this week's FB Live. I'm going to do a deep dive on why timing matters **SO MUCH** for hormonal healing—and how you can get the support you need to start syncing your life to your cycle.

Figure 22. Partial screenshot from email "FB Live: Stop Living Like a Man (...and get the body, career and life you want!)". Reproduced with permission.

The requirements for women to shape their behaviour around their natural, biological hormone cycles was justified by the statement: “You can eat all the right foods and get enough exercise, but if you’re not paying attention to **WHEN** you eat specific foods and how your exercise changes throughout your cycle, you won’t get results”. This statement not only reinforced neoliberal and healthist imperatives to perform ‘enough’ healthy behaviours, it positioned users who did not surveill their bodies or shape healthy behaviours around the

needs of their (female) reproductive body as failing to ‘get results’. Recommendations in the app itself were even more specific, varying not only by which phase of the menstrual cycle users were in, but which part of which phase. For example, users were encouraged to do intense yoga during the early part of the luteal phase and yin yoga during the late part of the luteal phase, and different exercises again during the menstruation, follicular, and ovulation phases. Such recommendations constructed healthy women as those who a) see their menstrual cycle as the defining force shaping how they live b) are willing to develop vast amounts of knowledge and planning to ensure they comply with their menstrual cycle’s requirements, and c) constantly surveill their bodies and behaviours to ensure they are achieving ‘results’. These intense requirements also set women up to fail, as women who fail to follow the advice exactly (i.e. ones who did yin yoga when they should have done intense yoga, or worse, did no yoga at all) were offered the subject position of being responsible for their unnatural, unhealthy female bodies.

6.3.3 Healthy women as productive (and wealthy).

Finally, apps also constructed health as a means for women with endometriosis to regain their status as empowered, productive citizens. Apps often constructed endometriosis as a threat to women’s ability to be productive. For example, Endo Diary’s Disease Education PowerPoint slides (shown in Figure 23) emphasised the “high burden” of endometriosis on society and the individual, which specifically included increased absenteeism from school and work, and increased socioeconomic cost. The ‘infographic’ aesthetic of the slide combined with the educational purpose of the section produced the economic burden of endometriosis as centrally important for women to understand, and functioned to position users who cannot work or that take time off work as economically unproductive and a burden on the state. This was reinforced by apps like Phendo and Flutter asking users to track how

‘productive’ they felt (discussed in Chapter 5) and MyFLO’s emphasis on women working to achieve their career goals (seen in Figure 24).

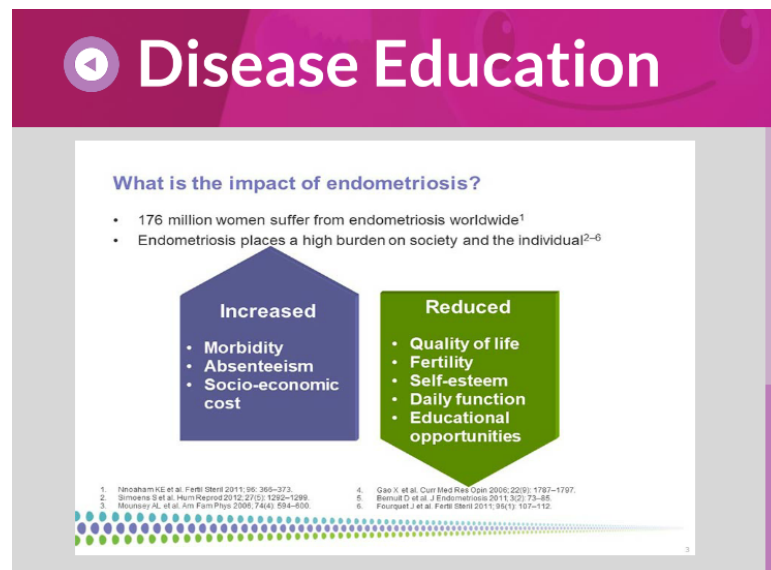


Figure 23. Partial screenshot from "Endo Diary PowerPoint Slides" in "Disease Education" feature of Endo Diary. Reproduced with permission.

Despite this emphasis on economic productivity, apps typically offered users limited and unrealistic representations of paid work. Endo Empowered and Flutter did not offer users any representations or references to women undertaking paid work. This may have functioned to position women’s experiences of endometriosis as unrelated to their ability to undertake paid employment, potentially resisting neoliberal discourses that people must be economically productive. However, both apps encouraged extensive consumption of expensive health foods and supplements, perhaps suggesting that they constructed work as symbolically incompatible with good health. The absence of work may also have reflected how both apps reproduced norms and practices associated with middle-class and traditional femininity, thereby positioning ideal users as wealthy enough for work to be unnecessary (or at least not central) to their lives.

Other apps privileged an idealised version of middle- and upper-class working lives characterised by flexible and autonomous control over working life. All workers were depicted doing white-collar, knowledge-based positions. For example, Phendo used an image of a person sitting in front of a computer surrounded by papers to represent work, while Endo Diary's video of Rose (a woman with endometriosis) was recorded in Rose's office, where she worked as an accountant. MyFLO offered users the most work-related images and content, through its 'focus' or 'Working in your Flo' feature. Figure 24 shows the advice offered to users as part of this feature about the best way to work during the luteal phase of the menstrual cycle to align with the female reproductive body's needs. This advice was captured under the heading called 'focus' and was symbolised by a cartoon brain. Associating work with focusing and the brain discursively produced work as knowledge-based, which was reinforced by the type of work being performed in the image.

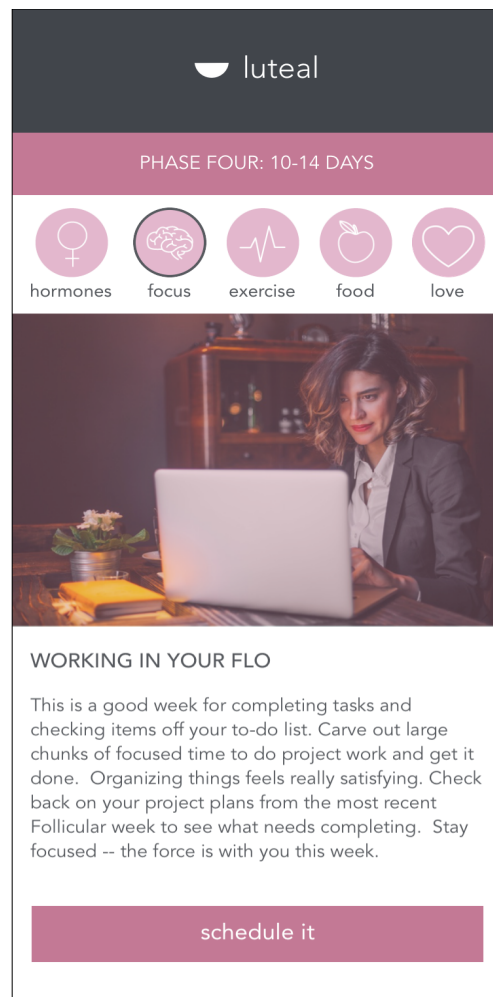


Figure 24. Screenshot of the "Working in your Flo" section of "Luteal" phase of "My Cycle Phases" feature of MyFLO. Reproduced with permission.

The image depicted a well-groomed, highly feminine woman using a laptop in some kind of non-work setting like a café or house. This communicated that the worker had agency and power over her work to work flexibly in a setting of her choice. Notably, the woman embodied a less 'natural' femininity than the women depicted in *Endo Empowered* and *Flutter* by wearing corporate clothing, bright red lipstick and styled hair. Thus, MyFLO constructed women in control of their reproductive bodies by drawing more on postfeminist ideas of economic empowerment and professional careers, rather than the passivity of traditional femininity (Gill, 2007; McRobbie, 2009). The importance of neoliberal ideals of empowered women was reinforced by the work tasks described in the subsequent text; again,

the worker was imagined to be doing project planning and management, and as having the agency to dictate how her time was spent. All references to work in the app constructed in similar ways, which excluded a wide range of working- and middle-class professions where workers are less able to control the content, location and structure of their working life. The image and text communicated that the ability to take up an economically empowered subject position by gaining control over one's reproductive body is only available to middle- and upper-class women.

6.4 Summary

In summary, apps constructed endometriosis as something to be managed and controlled by women with endometriosis. Apps offered a wide range of recommendations for how women should control endometriosis, such as biomedical interventions, self-management behaviours and major dietary changes. These recommendations drew on neoliberal ideals of citizenship by emphasising individual responsibility, agency, choice and self-surveillance. These ideals were present even when apps simultaneously constructed women with endometriosis as unable to affect their endometriosis in meaningful ways, making these behaviours important to do regardless of their impact on endometriosis. The rationale for undertaking behaviours regardless of their impact often reflected a healthist discourse that sees citizens as responsible for managing and improving their health. Furthermore, apps encouraged users to control their endometriosis in ways that drew powerfully on neoliberal and gendered discourses. While apps drew on slightly different constructions of how women should look and behave, all apps constructed health and healthy women in ways that conflated health with hegemonic femininity. Therefore, apps constructed women who successfully controlled their endometriosis in ways that were less about the endometriosis, and more about encouraging women to see the offered set of racialized, classed and gendered subject positions as their ultimate goal.

7 Discussion and Conclusions

Digital health apps are increasingly used by women to manage their health and illnesses, particularly related to reproductive health. Apps are important subjects of psychological study because app design is shaped by cultural norms and beliefs, influencing how users make sense of the world and themselves (Bivens & Hasinoff, 2018). This study used MCDA to explore how five endometriosis apps constructed endometriosis and people experiencing it. This analysis demonstrated that endometriosis apps drew heavily on biomedical, neoliberal and healthist discourses that intersected with discourses about women and femininity to construct endometriosis as a disease of the female reproductive body that women were responsible for managing. In this chapter, I consider these findings within the context of existing literature and discuss potential implications of these constructions for app users' lives. I also discuss some of the limitations of the research, reflect on the research process and offer some ideas for potential applications and future research.

7.1 Key findings and implications for users

The apps presented endometriosis knowledge as simple and cohesive, but the MCDA repeatedly revealed contradictions, highlighting competing discourses that were often present in the same app, often within one section of text or one app feature. The discourse analysis revealed that these competing truth claims about endometriosis and people with endometriosis were never acknowledged, which functioned to allow make them appear obvious and natural (Edley & Wetherell, 2001). These contradictions also meant apps made a wide range of potentially confusing subject positions available for users to take up, although some were made more appealing than others, such as the 'responsible consumer' position. These contradictions also reflect that several of the apps were commercial products and aligned with app developers' commercial interests while they also needed to align closely

enough with users' interests and capacities that they would continue using the apps and complying with self-tracking and recommendations.

7.1.1 Gendered embodiment.

The research findings showed that apps drew on biomedical and biological discourses to construct endometriosis as a physical disease caused by dysfunctional female reproductive anatomy and excessive, imbalanced female hormones. Apps used language and images drawing on themes of dirt and excess to construct endometriosis as causing abject menstruation, reflecting dominant discourses in Western societies considering normal female processes like menstruation to be part of the “monstrous feminine” (Laws, 1990; Martin; 2001; Ussher, 2006). Indeed, the MCDA demonstrated that apps constructed endometriosis as more monstrous than normal menstruation; more unclean, more medicalised and more likely to make women feel and act in negative and unfeminine ways (Chrisler, Marván, Gorman & Rossini, 2015). These findings are consistent with previous research demonstrating how biomedical literature (Jones, 2015) and biomedical professionals (Young et al., 2018) construct endometriosis (and women's illness generally) by pathologising the uterus and female sex hormones as the main markers of difference between female and male bodies. By producing women with women without endometriosis as natural and feminine, apps powerfully linked ‘normal’ reproductive functioning with ‘normal’ femininity, thereby constructing endometriosis as a threat to successfully performing femininity. These findings reinforce Seear's (2014) argument that biomedical constructions of endometriosis produced the non-endometriotic body as ‘normal’ and ‘natural’ in ways aligning with dominant versions of femininity.

Such negative constructions of the female reproductive body can negatively impact women's sense of embodiment. Women who hold more negative beliefs about menstruation

have been found to be more likely to experience self-objectification, while women with more positive attitudes are found to have more positive embodiment (Chrisler et al., 2015). When endometriosis-related pain and distress are produced as originating from within the (female) body, women may feel alienated by, separate from and let down by their bodies (Chrisler & Johnston-Robledo, 2018; Ussher, 2006). The present analysis also highlighted how apps also emphasised controlling ‘unfeminine’ menstruation-related bodily changes such as bloating, which Ussher (2006; 2011) argued can contribute to women’s distress and negative embodiment. Constructing these changes so negatively could exacerbate users’ existing distress; Facchin and colleagues (2018) reported women were more likely to be distressed about ‘unfeminine’ endometriosis symptoms that compromised their sense of womanhood. Additionally, Kressbach (2019) argued that menstruation tracking apps produce every aspect of menstruation as measurable and controllable, thereby objectifying a previously subjective experience and potentially contributing to women feeling alienated from their bodies. Both Ussher (2006) and Kressbach (2019) concluded that such constructions encourage women to take a biologically deterministic view of the self as controlled by their reproductive systems.

Moreover, apps often presented these constructions of endometriosis as simple and uncontested fact while simultaneously constructing endometriosis as mysterious and confusing. This could be an attempt to acknowledge the limited knowledge about endometriosis in ways that maintained the prestige and status of biomedicine and science as sources of knowledge about endometriosis. This is consistent with Seear’s (2009b; 2014) and Shohat’s (1992) analyses of why medical explanations characterise endometriosis as inherently enigmatic; as Seear argued: “medicine performs itself as heroic, progressive and omnipotent, while women and the feminine are performed as elusive, enigmatic and fundamentally disordered” (2014, p. 167). Ussher (2006) also argued that biomedicine discursively blames women’s bodies for being inherently confusing to exonerate the failings

of the (masculine, rational, truth-seeking) biomedical and scientific projects. These constructions may result in app users experiencing their bodies as confusing and considering their own embodied understanding of their experiences to be less valid or more unreliable than medical knowledge. The apparent contradiction between enacting endometriosis as simultaneously mysterious while being simple also enabled apps to produce endometriosis as capable of being mastered, but only by self-tracking and following expert advice. This may function to encourage women to see their bodies as inherently flawed, but as fixable through intense self-surveillance and discipline (Riley et al., 2018; 2019).

7.1.2 Digitised embodiment.

Health apps are part of a broader trend of using technology to conceptualise, visualise and monitor the human body, which may result in users experiencing new forms of ‘digitised embodiment’ (Lupton, 2017). Endometriosis apps attempted to render the body ‘knowable’ through both digital images of female anatomy and through the digital self-tracking practices that delved inside the body to collect data and subsequently rendered it visible (Lupton, 2017). They encouraged users to collect (and then view) data about bodily and behavioural functions typically considered to be sensitive or intimate, such as detailed descriptions of ovulation and menstrual fluids, sexual behaviour, digestive processes, mood, and coping strategies. Apps then transformed these data into visual forms like graphs and infographics, and applied algorithms that they stated would help users gain insight into their bodies and their health. Similar to the menstrual and fertility self-tracking apps in Kressbach’s (2019) sample, endometriosis apps produced the ‘self-knowledge’ gained through tracking to be empowering, which she argued functioned to encourage people to see their menstruation, health and their lives through a ‘datafied’ lens.

Haraway's (1991) concept of the 'cyborg' can help to illuminate how using apps to understand the body can blur the boundaries between human bodies and technologies. Lupton (2015) drew on Haraway's original idea to argue that apps and humans form 'digital cyborg assemblages', whereby people collect data and subsequently view a datafied version of their body in real time. Users can also respond to such datafied representations of their bodily functioning, in turn producing different data; for example, a user that sees that exercising alleviates endometriosis symptoms for the first time through the app may decide to exercise more, thus creating a dynamic relationship between app and human.

These 'digital cyborg assemblages' can be interpreted as extending the capacities of the human body, therefore producing new forms of embodiment that have been conceptualised as both potentially positive and negative for users. On one hand, Connor and colleagues (2015) used Haraway's cyborg theory to argue that women who have bodies that have traditionally been pathologised (they studied online pro-anorexia forums) used digital technologies to simultaneously embrace and reject constructions of their bodies as troubled to experience more positive embodiment. On the other hand, Lupton (2015; 2017) argued that the resulting datafied bodies created through calculations, predictions and comparisons reduce the complex capacity of bodily experience into appearing flat and one-dimensional. Similarly, Kressbach (2019) argued that the self-tracking and analytic features of popular menstrual and fertility apps may encourage women to understand their lives through their menstrual cycles by producing causal connections between logged symptoms and phases of the menstrual cycle as logical, authoritative explanations for women's experiences. Both conceptualisations reflect the fact that 'health data' may encourage users to internalise a narrow, numerical representation of what 'health' is and how successfully they are meeting it.

7.1.3 Empowerment.

Although apps varied in terms of who was constructed as having knowledge about endometriosis, they were consistent in their discursive positioning of women as lacking knowledge. A novel finding in this research was that natural and wellness apps (which overtly discredited biomedical knowledge about endometriosis) still relied on similar discourses to apps endorsing biomedical knowledge. Both types of app endorsed what Goldenberg (2010, p. 151) called a “masculine hero narrative of science”; where women with endometriosis are willing and able to understand their body better through the expert scientific knowledge offered by apps. Although apps offered users a potentially empowering subject position of becoming knowledgeable about endometriosis via app self-tracking, this knowledge was constructed as possible only when supported by data visualisation, algorithmic manipulation, and expert recommendations.

This may have positive implications for women trying to access credibility and legitimacy when interacting with medical professionals; Kressbach (2019) noted that tracking can situate women’s menstrual experiences within a dominant scientific paradigm more respected by doctors. However, the type of agency offered to women ultimately did not challenge expert knowledge and involvement in endometriosis management. This interpretation is similar to Goldenberg’s (2010) conclusion that ‘Pink Ribbon’ discourses offered women with breast cancer a version of ‘patient empowerment’ that was limited to undertaking constant self-surveillance, engaging in healthy behaviours, reporting evidence of cancer to doctors, and fundraising for medical research. Similarly, the MCDA identified several instances of apps encouraging women to raise awareness of endometriosis and collecting data to support expert biomedical and naturopathic research and intervention.

As the findings demonstrated, apps drew on neoliberal and healthist discourses to construct users as empowered to control their endometriosis (and their health) through their lifestyle choices. These findings align closely with other research; studies on health apps consistently conclude that apps frequently construct citizens as empowered to ‘take control’ and exercise choice over their health and healthcare options (Pettrakaki et al., 2018; Fotopoulou & O’Riordan, 2017). By applying the Foucauldian (1997) concept of ‘technologies of the self’, I argue that endometriosis apps may enable users to reflect and act on their bodies to achieve positive outcomes in ways that may very well be empowering for users. This may be particularly relevant for women with endometriosis who may not have received enough support for their endometriosis from state or commercial healthcare. For example, Lupton (2019) argued that some people who undertook self-tracking for health experienced an increased sense of agency and control over their bodies for their own interests, rather than simply internalising commercial and state interests by disciplining their bodies. She also noted that people often “actively and agentially performed self-tracking” (p. 11) by using self-tracking technologies to meet their own needs rather than passively following app instructions.

However, another interpretation is that apps are better understood using other Foucauldian (1990; 2006) concepts of “technologies of power” and biopower, in which state and commercial interests enlist citizens to undertake self-surveillance and self-discipline by constructing it as part of being a good, responsible and empowered citizen (Pettrakaki et al., 2018; Fotopoulou & O’Riordan, 2017; Sanders, 2016). This latter interpretation is supported by the fact that apps produced endometriosis as the result of making bad or risky choices about general health, which functioned to encourage users to desire and work towards general health as much as managing endometriosis symptoms. In this interpretation, app users with endometriosis may be more likely to feel burdened by the injunction to self-manage (Seear,

2009d). Given apps recommended self-management strategies focusing almost entirely on the individual making good choices across every aspect of their lives (especially relating to consumption choices), it is possible that app users who still experienced endometriosis symptoms could end up feeling like failures (Riley et al., 2018).

Moreover, apps always constructed physical and emotional health for women using colours, images and language idealising traditional and neoliberal performances of femininity. This analysis reinforced Riley and colleagues' (2018) argument that dominant discourses about women's health deeply reflect 'postfeminist healthism'. Endometriosis apps constructed healthy femininity in extremely narrow ways, excluding all people with endometriosis who do not identify as women, and all women who are not thin, able-bodied, White, young and middle-class. The apps often relied on postfeminist discourses that women could achieve healthy subject positions by constantly striving to improve their bodies and minds but did so in ways that were contradictory and required women to meet impossible standards (McRobbie, 2009). App users who exist outside of this extremely narrow and problematic ideal (people from non-Western cultures, non-White ethnicities, working class backgrounds etc.) may experience these constructions of 'healthy women' as alienating, harmful, or simply irrelevant to their lives and subjective experiences.

In this way, apps could be understood as less empowering for most women with endometriosis, and instead as a part of the postfeminist, multi-billion-dollar self-help industry offering people, especially women, the opportunity to improve themselves in line with dominant beauty and health ideals (Riley et al., 2018). These findings reinforce Sear's (2014) contention that endometriosis self-help literature produced women with endometriosis "as simultaneously responsive and responsible, passive and agentive, in ways that almost always function to the detriment of the disease cohort" (p. 172). My findings also support broader conclusions that women's bodies and behaviours are always subject to contradictory

and pathologizing forms of disciplinary power that produces women as risking failure on every front (Bordo, 1993; Connor et al., 2015; Ussher, 1997).

7.2 Limitations and reflections on this research

The limitations of this study were primarily shaped by the nature of apps as an object of study and the fast-changing nature of the ‘digital app environment’ more generally. Apps, like other highly interactive multimedia objects, distribute ideas, meanings and symbols across multiple screens, videos, buttons and interfaces (Hookway, 2017). Especially for the commercial endometriosis apps, apps were often part of a broader digital media environment comprised of company websites, emails, syncing to online diaries and encouragements to join Facebook groups. While app users easily navigate and create meaning through interacting with digital texts, my final dataset was comprised of static screenshots of the apps and accompanying emails. The MCDA methods I drew on (Kress & van Leeuwen, 2006; Machin & Mayr, 2012) offered useful frameworks for closely analysing the visual and linguistic features of single or few data points (such as an advertisement or a website) but offered less guidance about linking many small data points from across the app screenshots together to provide sufficient evidence for each analytic point. For example, I often found an app icon presenting a symbol discursively reinforced by an image and textual content all on separate screenshots, requiring all to be visually displayed and discussed in the analysis. Including examples from multiple locations ensured my analytic conclusions were valid but was challenging to articulate in a written form and represented the apps quite differently to how a user would experience them.

Additionally, using MCDA meant my research could not fully examine how human interactivity with the app shaped constructions of endometriosis, people with endometriosis and the subject positions made available to users (Light et al., 2018). Actor network theory

(ANT; Latour, 2005) considers social and cultural meaning to pass through (and be changed by) both human and non-human actors. Apps can be understood as non-human actors in this chain; app design, algorithms and affordances (the actions an app makes available to users) can transmit and transform social discourses (Light et al., 2018). Moreover, app self-tracking practices blur the distinction between those that produce app content and those that consume it (Bruns, 2008). Although using MCDA enabled identification of the social discourses informing app design and content, it did not offer a framework for engaging with the technical features and affordances of apps. Therefore, the multimodal analysis could have been enhanced by incorporating aspects of the ‘walkthrough’ method (Light et al., 2018). The walkthrough method was specifically developed to support social scientists without technical literacy to critically analyse the “implicit and (by design) apparently seamless process of engaging with a digital media object” (p. 885). Both the walkthrough and MCDA methods involve systematically observing an app’s functionalities, images and text, but the walkthrough method additionally offers explicit guidelines for analysing technical components. The ‘walkthrough’ method has been successfully used to examine how app interactivity contributes to shaping phenomena and people, such as Duguay’s (2017) study into how dating apps link with Facebook to make other users appear authentic and therefore safe to talk to. Understanding the specific role of interacting with endometriosis apps could be a useful avenue for further research.

Finally, the landscape of endometriosis apps (as with health apps and digital media more generally) is dynamic and rapidly evolving. In the nine months between collecting data and finishing this research, the Apple App Store added seven new apps in English about endometriosis, and an eighth was translated from French into English (see Appendix A for more details). Some apps in the sample received minor updates, some links to external websites within apps stopped working, and one app disappeared and then returned. This

changing environment does not make my findings unrepresentative or less valid, as I used a systematic sampling strategy to ensure my sample reflected how apps available at the time constructed endometriosis and people with endometriosis. Theoretically, a user of a new endometriosis app may be presented with different constructions and subject positions, although given how my analysis showed similar dominant discourses across the apps, these new apps may not mark a radical departure from existing apps. Additionally, a user's experience might be shaped by this constantly changing landscape; there are potential implications for accessing personal data should an app disappear, or stop being updated.

Nonetheless, MCDA proved a highly useful method for conducting research into the social construction of endometriosis within digital health apps. As argued by psychologists like Gleeson (2011), Reavey (2011) and Lyons (2000), my research findings were strengthened by looking beyond linguistic content to analyse how visual aspects like colour, images and symbols shaped meanings produced by the apps. It also offered valuable insights into how users might experience and understand a digital media object beyond the words they read, watch or hear. Therefore, such methods could be usefully used to examine apps (and other digital health technologies) focusing on other health conditions, not just for women.

7.2.1 Positionality and reflections on the research process.

My interpretations of the meanings being (re)produced by the apps are inextricably shaped by my own positionality, subjectivity and knowledge. Favaro and colleagues (2017) note that researchers analysing media data are also the audience. This dynamic was particularly pronounced in this study, given the ideal user imagined by most apps appeared to be people like me: a middle-class, White, cisgender woman with endometriosis - I even do yoga! There was sometimes a tension between being both a researcher and someone interested in managing their symptoms of endometriosis. Even while critically interrogating

the discourses reflected in endometriosis apps, I simultaneously found myself internalising some constructions: perhaps self-management was the best solution, and perhaps my lifelong love of bread was to blame for my endometriosis. Rather than weakening my analytic insights, I consider my awareness of these internal conflicts to have strengthened my awareness of the possible subject positions being made available, which increased the nuance of my insights (Gough, 2003).

Additionally, I experienced strong reactions to some constructions and weak reactions to others, particularly during the early stages of data familiarisation. Using Gough's (2003) guidelines for doing reflexivity, I noticed these different reactions and readings closely to interrogate how they might be shaped by my own subjectivity. I noticed I was particularly attuned to gendered, racialized, classed and heteronormative social discourses about women, reflecting my feminist knowledge and commitment to intersectionality. Conversely, biomedical and healthist discourses were often less readily apparent to me given how normalised they were within my upbringing and professional career. Once I had identified this pattern of responding, I was able to look more closely at both types of reaction to consider alternative possible interpretations and subject positions.

Undertaking this qualitative multimodal discourse analysis required me to draw on shared cultural knowledge and other empirical and theoretical work to interpret how apps constructed endometriosis and people with endometriosis. While I approached the analysis from an open and exploratory position, I was also aware that the range of possible readings of a media text tends to be constrained by the dominant norms and beliefs circulating within particular historical and sociocultural contexts (Favaro et al., 2017). Therefore, some aspects of the apps surprised me by how they did not reflect dominant discourses of endometriosis even while reinforcing others. For example, I went into the analysis expecting to find dominant social and biomedical discourses compelling women with endometriosis to

reproduce. Therefore, I was surprised that apps were relatively silent on the issue of fertility. While several of the apps constructed infertility as a major and negative symptom of endometriosis, women with endometriosis were constructed as ideally able to make informed and empowered decisions to achieve pregnancy if desired.

Finally, I found the process of conducting discourse analysis of media data to be a very solitary experience. I was not part of a 'lab' or cohort of students supervised by the same academic, so I had limited opportunity to share ideas with people working on similar projects. Moreover, I conducted this feminist, critical, qualitative research project while enrolled in a psychology department primarily producing empirical and positivist quantitative work, and my undergraduate psychology training had not prepared me to undertake research using qualitative methods. Therefore, completing this research required me to embark upon a steep learning curve about conducting MCDA alone, and unlike qualitative research with participants, the apps in my sample never spoke back to me. This was managed by testing my analysis and interpretations with support from my supervisor and with the Qualitative and Critical Collective (QuaCC), a small student group we established to facilitate learning about critical and qualitative research. Furthermore, a longer period of research would have enabled more collaborative research using participants, perhaps drawing on participatory research methods in which people with endometriosis and I could co-produce the research problems, analyses and applications in ways benefitting them (Vaughan, 2015). While participatory research does not suit all research questions and goals, it is a useful way to conduct research with marginalised groups to address social issues and challenge power.

7.3 Looking forward

There is never one fixed or 'correct' interpretation of qualitative data, and this study's design did not offer insight into how users other than me might make sense of the meanings

produced by endometriosis apps, or how they might take up or resist different subject positions offered (Favaro et al., 2017). Girls and women have been shown to actively negotiate, transform and resist meanings identified in media texts like magazines (Durham, 2004; McRobbie, 1991). Jewitt (2009) and Reavey (2011) encourage researchers to combine research using MCDA with participant-based research to strengthen claims about discourses present in media texts. Therefore, a natural extension of the current study could employ interviews and focus group methods to examine how participants with endometriosis experienced using the endometriosis apps, how they interpreted the visual and linguistic content of the apps, and how they engaged with the technical self-tracking and social media affordances of the apps. This kind of participant-based research could also offer insight into the kinds of app features and constructions of endometriosis that people with endometriosis might find helpful.

Overall, the findings of my MCDA research contest popular claims that Femtech apps are inherently empowering. However, it is possible that more feminist apps and other self-tracking technologies could be designed to resist biomedical, neoliberal and postfeminist discourses present in endometriosis apps. Such apps could decouple constructions of endometriosis and health from hegemonic feminine and neoliberal ideals; they could shift from blaming distress on the individual reproductive body to more adequately acknowledging the structural economic and social factors shaping health and illness. They could construct health as more than just having typical reproductive and biological functioning and use images of a more diverse range of people living a wider range of lives. The apps could offer users more affirming ways to improve their subjective sense of health and wellbeing without holding them responsible for experiencing pain or illness. Sanders (2016) described how women could use self-tracking as subversive avenues of resistance to biopower and patriarchy; she imagined users shifting away from seeing self-tracking as measuring progress

towards a pre-determined body or health ideal, and instead see self-tracking technologies as “tools for inventing oneself as something new” (p. 56). It is important to acknowledge that people with endometriosis likely sought an app to achieve relief from endometriosis-related pain or distress, so health goals cannot be subverted entirely. Instead, endometriosis apps could explore a wider range of parts of people’s lives (such as spending time with family and friends) to consider how they impact their endometriosis symptoms and/or their overall subjective wellbeing.

Self-care could form a central part of this, but not necessarily in the same way as imagined by endometriosis apps. Ussher (2006; 2011) and Chrisler and Johnston-Robledo (2018) argued that performing self-care can be liberating for women by increasing appreciation of their bodies and reducing self-objectification and alienation. This radical conception of self-care differs by the version espoused by endometriosis apps, as it involves supporting women to enjoy activities that do not serve gendered and patriarchal body work, psychological improvement projects, or neoliberal injunctions to consume expensive products like organic food and dietary supplements. Also, this vision of self-care does not necessarily see the self as always separate from others; it could focus on enjoying group activities or building body-positive communities (Chrisler & Johnston-Robledo, 2018). Although women with chronic illnesses such as endometriosis may find it difficult to appreciate their body or perform some self-care activities, apps could contribute to users’ positive embodiment by offering more accessible ideas and less pathologising constructions.

Finally, there are significant risks and ethical concerns associated with commercial entities gaining access to large amounts of sensitive, potentially identifiable personal information. Endometriosis apps typically provided little or vague information about how they stored, used, and shared personal health data. According to New Zealand’s Office of the Privacy Commissioner (2014), ambiguous data policies are typical; 85 percent of apps in

online failed to offer clear privacy information, which precluded users from being able to give informed consent. Several menstrual and fertility tracking apps have been found to share health data with Facebook, including Flo, the most downloaded period tracker app in the Apple Store (Privacy International, 2019). In one extreme case, shared data included all data inputted by users and app-generated data (i.e. stage of the user's menstrual cycle calculated from user data; Privacy International, 2019). Given the New Zealand government is increasingly encouraging users to manage their health using apps and other digital health technologies (Ministry of Health, n. d.), it is important that apps available in New Zealand are required to meet New Zealand's privacy legislation, similar to how the European Union requires all countries operating in the EU to comply with the General Data Protection Regulation 2016 regardless of the laws in their home country (GDPR, 2016).

7.4 Concluding comments

Women with endometriosis face considerable challenges; not only must they cope with the material, embodied experience of endometriosis, they also navigate medical and social worlds that already see women's pain as normal and their bodies as monstrous. Although apps are marketed as empowering women, this exploratory study provides evidence that endometriosis apps construct endometriosis in ways that reinforce rather than resist dominant social constructions about endometriosis, women and their bodies. Apps powerfully constructed endometriosis as an abject, confusing and bad disease caused by individual failure, offering women few opportunities to take up a more positive and holistic relationship to their body and self. Instead, apps offered users a clear solution that relied on users seeing their endometriosis as controllable through intense self-monitoring, self-tracking and self-discipline. Again, this study showed that apps reinforce rather than resist the dominant discourses shaping individuals in Western society; apps constructed self-tracking as useful for becoming responsible, healthy, feminine citizens. I have argued that while apps offer

potentially new and empowering ways of using digital technology to understand and shape the body, the current study showed that endometriosis apps more accurately reflect a retrenchment of patriarchal and neoliberal power dynamics rather than a more inclusive way forward for women and people with endometriosis. Endometriosis apps may mark a shift away from endometriosis being a 'silent disease', but this research shows we must equally enquire into what type of selves and citizens endometriosis apps encourage users to be.

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Appendix A. Endometriosis apps not in sample*Apps that did not meet sampling criteria during data collection*

Name of app	App developer/owner
51 Ways to treat endometriosis	Revolution Games, Inc.
Endometriosis Diary	cellHigh LLC
Endometriosis Support	My Health Teams
Pain Companion	Sanovation AG
The Endometriosis Diet	Iluka Blue Pty Ltd.

Apps that have been developed since data collection

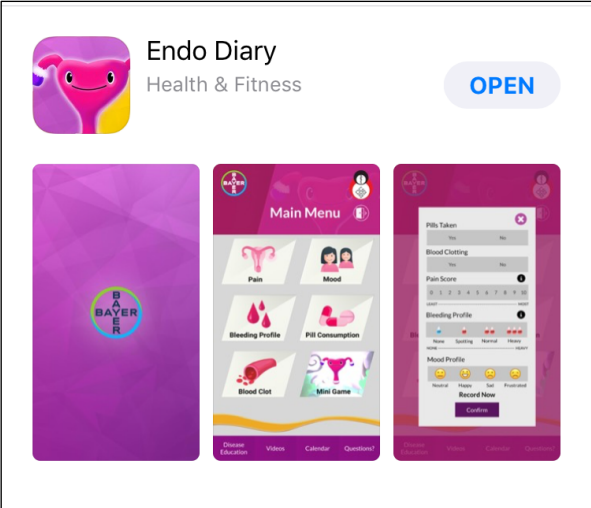
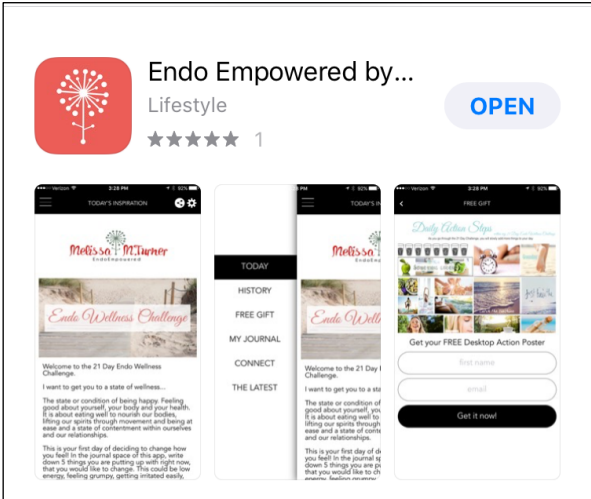
Name of app	App developer/owner
Endobaby	Endobaby
Living with Endometriosis	Kanoa Matton
My Endo App (English version)	My Endo App
Nezhat Endometriosis Advisor	Inframatic LLC
Pelvic Pain Chronicles	M. I. S. Connection LLC.
SurrEndo	Ess Cee
Visana: Endo & Period Pain	Visana Health, Inc.
YES GOD WELLNESS	The Transformation Period Inc.

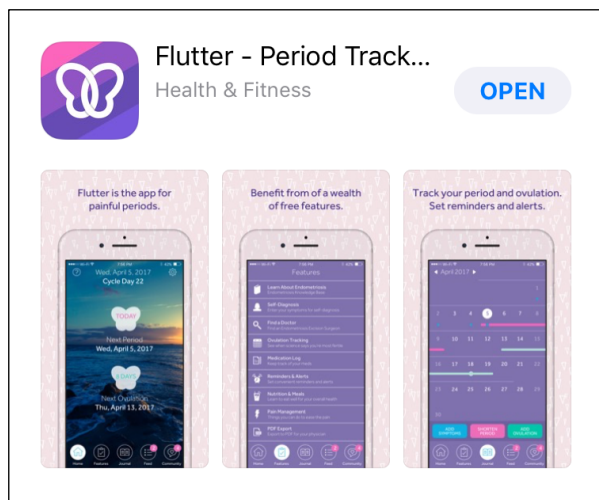
Appendix B. Summary of codes

App aesthetic	Pink		
	Feminine/female		
	Natural		
	Scientific		
	Underdeveloped		
Nature of endometriosis	Female biology	Pain	
		Infertility	
		Abnormal menstruation	
		Emotions/mood	
		Hormones	
	Beyond female biology	Digestive problems	
		Pain	
		Loneliness/isolation	
	Severe/all-encompassing	External world	
		Internal world	
		Curable/ incurable	
		Visible/invisible	
		Mind/body	
		Confusing/simple	Simple for doctors
			Confusing for doctors
Confusing for women			
Controllable		Easy to control	
		Hard to control	
Uncontrollable			
No description			
Endometriosis causes	External causes	Food	
		Toxins	
	Internal causes	Hormones	
		Uterus	
		Behaviours	
		Thoughts	
		Immune system	
	No claims about cause		
	Knowers of endometriosis	Medical doctors	
		Naturopathic experts	
Women with endometriosis			
App developers			
Recommendations	Self-tracking	Self-surveillance	
		Self-knowledge	
		Self-control	
		Empowerment	
	Data visualisation	Empowerment	
	Biomedical	Medication	
		Surgery	
		Diagnosis	
	General health and wellness	Food/eating	

		Supplements
		Exercise
		Change thoughts or behaviours
		Buy products
		Spend time
		Engage with nature
	Optimise self	
	Seek happiness	
	Take responsibility	Choices/decisions
People with endometriosis	Women	
	Responsible/irresponsible	
	Survivors	
	Negative emotionality	Worried/fearful/stressed
App privacy		
App functionality	Self-tracking	
	Data visualisation	
	Diagnosis advice	
	Journal	
	Social network	
	Information/advice	
	Games/challenges	
	Research	
	Case studies	

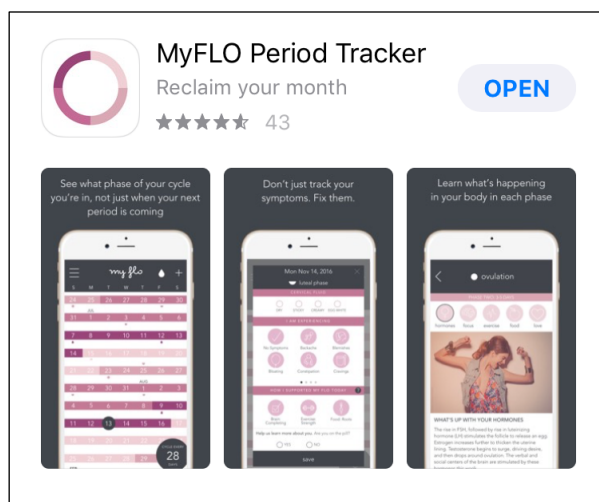
Appendix C. Additional details of app listings in Apple App Store

Screenshot from Apple App Store	Description
	<p>Endo Diary</p> <p>Advertising panels show screenshots from the app, including (L- R): the loading screen with Bayer logo, the Main Menu screen and the tracking screen that appears when users click one of the first five icons on the Main Menu.</p>
	<p>Endo Empowered</p> <p>Advertising panels show screenshots from the app, including (L- R): the first daily challenge message, the navigation panel to different sections of the app, and a preview of the ‘Daily Action Steps’ poster.</p>



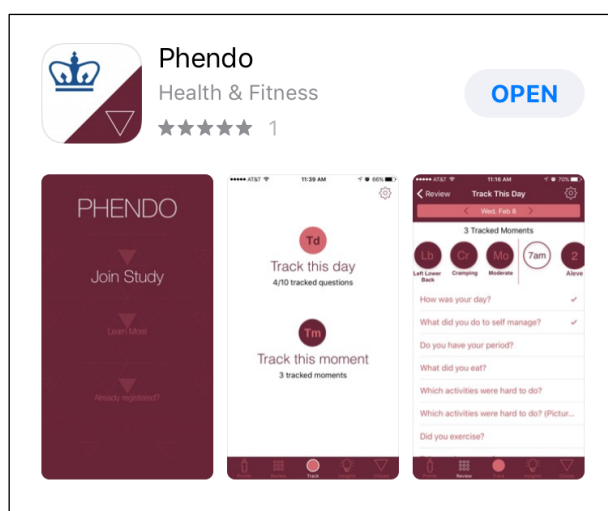
Flutter

Advertising panels show descriptions and screenshots from the app, including (L-R): the main page of the app customised with a wallpaper, the Features page, and the period and ovulation tracking calendar.



MyFLO

Advertising panels show screenshots from the app, including (L- R): the tracking calendar, symptom tracker and an example from the ‘My Cycle Phases’ advice.



Phendo

Advertising panels show screenshots from the app, including (L- R): the main page of the app that users see prior to joining the study, the main tracking page, and an example of the questions included in the ‘Track this Day’ feature.