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The missed disease? Endometriosis as an example of 'undone science'

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Nicky Hudson is a medical sociologist with particular expertise in social and cultural significance of reproduction, infertility and assisted reproductive technology. Her work also focuses on the sociology of chronic illness. Uniting these themes is an emphasis on questions of individual-biomedicine-society relations. She has received funding for her work from the Economic and Social Research Council, the Wellcome Trust, Foundation for Sociology of Health and Illness, and the National Institute for Health Research. Her research is characterized by a strong commitment to interdisciplinary collaboration, social translation and impact. She leads the Centre for Reproduction Research, an interdisciplinary centre of expertise dedicated to the production of scholarship on the social, cultural and political aspects of human reproduction, based at the Faculty of Health and Life Sciences at De Montfort University (UK).

Abstract Endometriosis is a chronic gynaecological condition which has been referred to as the 'missed disease' due to its unclear aetiology and inconsistencies in its diagnosis and management. Unlike other long-term conditions such as diabetes and asthma, endometriosis has remained largely ignored in government policy and research funding globally. Drawing on scholarship from the growing field of 'ignorance studies', this paper considers how ambiguity around endometriosis is part of a wider constellation of discursive, material and political factors which enrol certain forms of knowledge whilst silencing, ignoring or marginalizing other forms of knowledge. It uses concepts of 'undone science' and 'wilful ignorance' to explore how an absence of knowledge on endometriosis is a result of structural, cultural and political processes and forces which privilege certain voices and communities. This paper suggests that the association of endometriosis with historically specific constructions of menstruation and women's pain has informed contemporary imaginaries around the condition, including ideas about women being somehow accountable for their own illnesses. Applying an ignorance lens demonstrates how the legacy of invisibility of endometriosis shapes its place in the present political and social arena, and is reflective of a process of undone science. The paper concludes by arguing that the social and political significance of endometriosis as a chronic, life-limiting condition which affects millions of women globally continues to need attention, illumination and critique. 

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Introduction

Endometriosis is described as a chronic gynaecological condition characterized by a diverse and complex range of

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symptoms including chronic pelvic pain, painful sex, heavy bleeding and infertility. It has been referred to as the 'missed disease' (Overton and Park, 2010) due to its unclear aetiology and inconsistencies in its diagnosis and management. Considered relatively rare even in the early 1980s, cases have skyrocketed in recent years (American Endometriosis Association, 2009, see Seear, 2014). Estimates suggest that it affects 10% of women, or 178 million women globally (Rogers et al., 2009), and that 47% of infertile women may have the condition (Meuleman et al., 2009). Controversially, endometriosis experts have hypothesized that most, if not all, women have the symptoms of endometriosis to some extent (Evers, 1994, see Jones, 2015). This rapid upward trajectory has led to suggestions that endometriosis represents a 'modern epidemic' (Seear, 2014).

Somewhat counter-intuitively, whilst cases of endometriosis have risen, persistent complexities in the classification and identification of the disease mean that the average time to diagnosis is still 7.5 years in the UK (NICE, 2017). Studies show how women experience delegitimization of their symptoms before, during and following diagnosis, reporting that they are disbelieved by professionals or that their concerns are 'fobbed off' (Denny, 2004a, 2009; Seear, 2009a). Despite an exponential increase in the number of women with the condition [more women are affected by endometriosis in the UK than diabetes (Simoens et al., 2012)], it presents somewhat of a conundrum that, until very recently, endometriosis has remained virtually invisible in the public imaginary. Unlike other long-term conditions such as diabetes and asthma, which have a similar social and economic disease burden and have become public health priorities in a number of first-world contexts (Simoens et al., 2012), endometriosis has remained largely ignored in government policy and research funding globally. This has led to important ongoing omissions in understanding of the condition; its aetiology and symptomology; and how it affects lives, families and societies. Pressing questions endure regarding how endometriosis continues to be rendered invisible, who is or is not involved in knowledge production about the disease, and why timely diagnosis remains elusive for many women.

Drawing on scholarship from the growing field of 'ignorance studies' (Frickel et al., 2010; Gross and McGoey, 2015; Hess, 2007, 2016; Kempner et al., 2011; Kempner, 2014; Tuana, 2004, 2006), the sociology of diagnosis and medical classification (Brown et al., 2011; Hollin, 2017; Jutel, 2011; Latimer, 2000; Nettleton, 2004) and feminist empirical studies of women's experiences of endometriosis (mainly in the UK, USA and Australia, e.g. Culley et al., 2013a; Denny, 2004b, 2009; Denny et al., 2010; Hudson et al., 2016; Seear, 2009a,b, 2014; Whelan, 2007), this paper considers how ambiguity around endometriosis is part of a wider constellation of discursive, material and political factors which enrol certain forms of knowledge whilst silencing, ignoring or marginalizing other forms of knowledge. It uses the concept of 'undone science' (Frickel et al., 2010; Kempner et al., 2011) to explore how an absence of knowledge on a particular subject (endometriosis) is a result of structural, cultural and political processes and forces which privilege certain voices and communities (Kempner et al., 2011). It considers how endometriosis has been 'willfully

ignored' (Tuana, 2006), and therefore proposes that knowledge about endometriosis has been inhibited by underinvestment in scientific research, despite the fact that it has been identified as worthy of policy attention and scientific research by women who are affected (Frickel et al., 2010).

This paper draws on methods of critical reflection (Hauskeller and Beltrame, 2016; Hudson et al., 2020), which involves examination of the implications of a social phenomenon by drawing and reflecting on existing published findings and theoretical concepts. It begins by examining the historical and political situatedness of ignorance around women's bodies and health in the context of androcentric biomedicine, exploring via existing literature how this context shaped the 'discovery' and definition of endometriosis. Second, it considers the persistence of uncertainty around the formal identification and classification of the disease in contemporary biomedicine, drawing on scientific statements and classification systems, and critical work from social science scholars of classification and diagnosis. Finally, drawing on published research about women's lived experience of endometriosis, focus is given to the ways that these experiences have been excluded in processes of policy and research agenda-setting, medical categorization and treatment pathways. The paper concludes by considering the implications of ignorance on chronic illness for public health policy, medical practice and patients. It considers how new social movements, grounded in the lived experiences of women in relation to their menstrual health, are gradually shifting the policy lens on to conditions such as endometriosis. It suggests that bringing together the concepts of undone science, wilful ignorance and non-knowledge with ideas about the situatedness of diagnoses and processes of biomedical uncertainty can provide a new reading of the long-standing invisibility of a socially contested and gendered condition.

Endometriosis, menstruation and biomedicine: A historical note

The term 'endometriosis' comes from the Ancient Greek, meaning an abnormal condition of the uterus (Older, 1984). It is commonly described as a chronic inflammatory condition which occurs when endometrial-like cells are found outside the uterus in the pelvis. During the monthly cycle, this tissue responds to hormonal changes in the body causing the cells to grow, then break down and bleed. However, unlike with menstrual blood which leaves the body during menstruation, this blood has nowhere to go, causing inflammation and the formation of scar tissue (NICE, 2017). Adhesions can form from this scar tissue, leading to considerable abdominal pain for many women. Whilst a range of theories exist about the origins of the disease, understanding about its precise aetiology remains scarce.

Most accept endometriosis as a relatively recent discovery, given the dearth of evidence about its existence prior to the early 20th century. The condition is described as being first identified microscopically by Karl von Rokitansky in 1860 (Batt, 2011). However, use of the term 'endometriosis' is usually credited to the Canadian gynaecologist John Sampson, who, in 1921, first proposed the (debated) theory of retrograde menstruation as the cause (during menstua-

tion, while most of the blood and uterine lining leaves the body via the vagina, retrograde menstruation postulates that some cells travel back up the fallopian tubes and into the peritoneal cavity. In cases of endometriosis, the theory is that some of these cells deposit in the pelvis and become endometriosis (Benagiano and Brosens, 2011; Jones, 2015; Liu and Hitchcock, 1986)). Whilst it is thought of as a modern condition, it has been suggested that endometriosis may have existed for as long as 2,500 years due to descriptions of Hippocratic doctors treating women with chronic pelvic pain (Nezhat et al., 2012). Links have been made between endometriosis and historical descriptions of hysteria (i.e. ideas about behavioural disturbances believed to be caused by the uterus) which, it has been argued, may have been undiagnosed cases of endometriosis (Nezhat et al., 2012). Due to hysteria's constructions of women as unstable, gender deviant and unable to bear children, a number of authors have suggested that endometriosis and hysteria share common underlying sociohistorical discourses (Jones, 2015; Seear, 2014; Whelan, 2007; Young et al., 2019). Nezhat et al. suggests that if it is true that hysteria could represent undiagnosed cases of endometriosis, 'this would constitute one of the most colossal mass misdiagnoses in human history, one that over the centuries has subjected women to murder, madhouses and lives of unremitting physical, social and psychological pain' (Nezhat et al., 2012: 1).

Given the relation of endometriosis to menstrual function, early scientific thinking about menstruation is particularly significant for understanding the ways in which endometriosis came to be defined and the links with hysteria highlighted. In her work on the history of menstruation, Strange (2000) suggests that from the mid 19th century, the medical definition of menstruation was almost exclusively expressed in terms of pathology and a failure to reproduce. The 'menstruous' woman was perceived as physically unwell and psychologically vulnerable (Strange, 2000). Despite scientific thinking that menstrual flow would enhance 'personal loveliness', physicians otherwise referred to menstruation as an 'unfortunate, unpleasant and distasteful subject to address and certainly one from which women themselves should be spared' (Strange, 2000: 609). This early gynaecological discourse around women's bodies saw them as disordered and in need of control (Strange, 2000; Young et al., 2019). Women were thought to be biologically inferior to men and therefore unable to participate in society in an equivalent manner (Strange, 2000). They were also believed to be particularly prone to sickness, with their illnesses thought to emanate from their reproductive systems (Scambler and Scambler, 1993). 'Diseases of women' (Strange, 2000) were commonly viewed as a result of women's psyche, and as related to reproduction and a failure to fulfil their biological destiny of motherhood (Young et al., 2019). Historically speaking, endometriosis can therefore be situated as part of a wider set of omissions and constructions relating to women's health, whereby the masculine has been used as the standardization of what constitutes health, and illnesses common to women are systematically ignored or misattributed as evidence of mental illness, deviant behaviour or a lack of self-care.

In this sense, endometriosis shares affinities with a range of other gendered conditions. Scholarship on biomedical uncertainty and liminality demonstrates how underdiagnosis

and misrecognition of particular conditions is historically situated, illustrating how gendered frameworks have operated to delegitimize certain bodies and symptoms (Greenhalgh, 2001; Kempner, 2014; Nettleton, 2004). Fibroids, polycystic ovary syndrome, fibromyalgia and migraines (Kempner, 2014) are further examples of conditions in which painful and disabling symptoms (mostly amongst women) have been systematically and historically dismissed, ignored or delegitimized. Sharing characteristics with endometriosis, these examples of 'missed' diseases collectively draw our attention to the ways that practices of ignorance are entwined by and with practices of oppression and exclusion (Tuana, 2004), helping to contextualize contemporary complexities of diagnosis, and struggles for recognition and legitimacy in relation to expert knowledge. The systematic non-production of knowledge about women's health, in particular, can be located within a historical context of (white) androcentric biomedicine, setting the scene for an understanding of contemporary forms of ignorance. Whilst non-production of knowledge is not exclusive to women's health, feminist scholars have drawn our attention to the systematic failure of scientific thought to account for women as agents and subjects, and for their experiences to be included in determining the definition of problems given attention by science (Fox Keller, 1982; Haraway, 1988; Harding, 1989; Vostral 2018), and this work has been an exceptionally rich source of reflections about silence and its significances, exemplifying the character of ignorance in a range of arenas (Gross and McGoey, 2015).

Classificatory ambiguity and the production of non-knowledge

Since it was first formally identified and named in 1921, endometriosis has remained socially and medically disputed. Developments in categorization of the condition emerged with new surgical and diagnostic techniques; for example, new pelvic endoscopic techniques in the 1940s allowed differentiation between endometriosis and conditions such as appendicitis and salpingitis (Benagiano and Brosens, 2011). The introduction of laparoscopic biopsies in the 1980s also increased the efficiency of diagnosis (Seear, 2014). However, conclusive evidence about the aetiology of endometriosis is still absent, and a range of theories, including those relating to genetic factors, faulty immune responses, environmental factors and retrograde menstruation (Rolla, 2019), exist. There is also a lack of non-invasive diagnostic tests and, despite advances in the development of biomarkers (a naturally occurring molecule, gene or characteristic by which a disease can be identified) in diagnoses of a range of other diseases, no reliable biomarkers currently exist for endometriosis (As-Sanie et al., 2019; Rolla, 2019). Therefore, whilst some developments in diagnosis and treatment have been made during the 20th century, progress has been slow and production of non-knowledge – that is, the choice to accept gaps in a field of knowledge (Hess, 2007, 2016; Kempner et al., 2011; Kempner, 2014) – persists.

The variable presentation of endometriosis means it is often confused with other conditions affecting the pelvic area, including irritable bowel syndrome and appendicitis

(Seear, 2014). Since its emergence in the 1980s, the gold standard technique for diagnosing the condition remains laparoscopy (a surgical procedure that allows a surgeon access to the inside of the pelvis using minimally invasive techniques, also known as 'keyhole' surgery), but even when this procedure is performed, there can be confusion about the presence, extent or type of endometriosis (Johnson et al., 2017). Endometriosis is (usually) cyclical, with endometrial deposits responding to monthly hormonal changes in the body, and presents differently in different women. Some women have chronic and recurring monthly pelvic pain and heavy bleeding, other women have problems with fertility, and other women have no symptoms at all (Culley et al., 2013b). The impact of endometriosis on fertility is also unclear, but it is suggested that 47% of infertile women have endometriosis (Meuleman et al., 2009). This differential presentation is a central feature of the classificatory ignorance surrounding endometriosis, and has become a defining feature of the disease.

As there is no cure, contemporary management of endometriosis focuses on symptom relief, which can involve analgesics, hormonal therapy, and both minimally invasive and radical surgery (NICE, 2017). Treatment of endometriosis with hormones (including, for example, the oral contraceptive pill), which attempts to reduce the response of the endometrial cells to natural hormone production, began in the 1940s. These treatments work by limiting the impact of oestrogen on the endometrial deposits, which reduces inflammation (Benagiano and Brosens, 2011; Rolla, 2019). Given their perceived alignment with gender identity (i.e. the idea that oestrogen = femininity), the use of sex hormones to treat women adds to the sense that women's bodies are disordered, deficient and therefore in need of intervention (Oudshoorn, 2003; Roberts, 2007; Seear, 2014). Surgical treatments for the condition gained popularity in the 1970s when laparoscopic techniques were introduced with the aim of excising endometrial deposits in the pelvis (Benagiano and Brosens, 2011). However, the use of surgery is reserved for women considered to have more severe forms of the condition, and given there is variability in diagnosis, many women miss out on more specialized treatments.

Given its ambiguous status and a lack of scientific knowledge about its aetiology, a number of myths surrounding the disease have developed. The most persistent of these is that it is a 'career woman's' disease, as clinicians reported that women who had children later in life were more prone to the disease (Wood et al., n.d.). This idea – that women's behaviour made them susceptible to endometriosis – persisted into the 1990s and led to the practice of routinely advising women to become pregnant in order to reduce symptoms (because the absence of menstruation reduces symptoms). The idea that girls and younger women do not experience endometriosis was also a historical belief, which circulated due to the fact that earlier invasive methods of diagnosis (using laparotomy, which involves a large incision in the abdomen) meant younger women were less likely to be diagnosed, leading to the myth that only women in their 30s and 40s could have the disease (Wood et al., n.d.). Discourses around the condition being rooted in women's personality and behaviours (e.g. anxiety or perfectionism) have also been highlighted (Seear, 2014).

Given the variation in symptoms and the uncertainty around management, treatment often proceeds on a trial-and-error basis, with women commonly being prescribed the birth control pill as a first stage treatment (ESHRE, 2013; NICE, 2017). The management of endometriosis is therefore complicated by the fact that some treatments also inhibit conception, and therefore women (and their partners) are required to choose between symptom relief and fertility/childbearing (Culley et al., 2013a). For women whose fertility is affected by endometriosis, treatment may focus on enhancing attempts to conceive, rather than on relief from pain. However, uncertainty exists here too. Whilst for those with mild-to-moderate endometriosis, operative laparoscopy can help to improve ongoing (spontaneous) pregnancy rates and may also be beneficial prior to the use of reproductive technology, evidence about the overall efficacy of surgery in cases of endometriosis-related infertility is largely inconclusive (ESHRE, 2013). Treatment for endometriosis is therefore another important site of ambiguity and uncertainty, adding to the construction of endometriosis as an enigmatic entity.

A number of scholars of endometriosis have highlighted the ontologically contested nature of the condition, establishing the various ways that endometriosis has remained disputed, uncertain and contingent since its emergence (Seear, 2014; Whelan, 2007). Kate Seear's work is significant in this regard; she draws attention to the incomplete character of understanding about endometriosis, and asks if we can 'even speak about "endometriosis" practice/medicine/etc. when there appears to be a lack of consensus about the central ontological referent?' (Seear, 2014: 4). Elaine Denny develops the categories of 'diagnostic uncertainty' and 'trajectory uncertainty' in order to demonstrate how biomedical expectations relating to endometriosis are contingent and unstable (Denny, 2009). Building on this work, the idea of endometriosis as an 'indeterminant' entity is valuable when referencing the heterogeneity and ontological and epistemological uncertainty of endometriosis. The concept of indeterminacy refers to a phenomenon's multifaceted, contingent and unstable nature (Hollin, 2017). In the case of endometriosis, the disease's uncertain ontology and the persistent ignorance surrounding its form and trajectory are constitutive of this indeterminacy.

Attempts have been made by medical and scientific bodies to reduce or omit this ambiguity via the classification of endometriosis. These attempts are aimed at reducing biomedical ambiguity and increasing certainty about the existence and trajectory of the disease. Scientists themselves have discussed how there is no single classificatory system which adequately categorizes endometriosis (Johnson et al., 2017). Several attempts have been made, including schemas originating in the 1970s which were made possible by developments in laparoscopic techniques (Rolla, 2019). The best known of these is the revised American Society for Reproductive Medicine system (ASRM, 1997) which includes five stages: minimal, mild, moderate, severe and deep infiltrating. The stages relate to the type, extent and location of the disease, and include a grading system, with diagrams, for clinicians to record the observable extent of the disease. In 2014, the World Endometriosis Society held a consensus on the classification of endometriosis at the XII World Congress on Endometriosis,

with representatives from 29 medical and non-medical organizations. Delegates concluded that ‘until better classification systems are developed, we propose a classification toolbox’ (Johnson et al., 2017: 323), meaning that existing systems should be utilized in conjunction in the absence of clear consensus around classification. The scientific consensus around endometriosis is therefore that there is no consensus. Professional and policy bodies, such as the European Society for Human Reproduction and Embryology (ESHRE, 2013) and the National Institute for Care and Excellence (NICE, 2017), have produced guidelines on the management and care of women with the condition. This guidance draws on current evidence to provide a treatment trajectory for the patient, and to shape and communicate best practice for care. Given that the evidence base around the condition is limited, scientific consensus is lacking, and the long-standing mis- and under-recognition of the condition, attempts to standardize treatment – whilst welcome – remain built on an incomplete foundation, and one which prioritizes ‘objective’ knowledge.

Attempts to order and categorize the condition can be thought of as ‘uncertainty work’: practices which are carried about by scientists in order to reconcile uncertainty and scientific authority (Shackley and Wynne, 1996). In this way, uncertainty and disease boundaries are actively managed by recognizing certain types of uncertainty (e.g. the lack of clarity over a cause) and strategically ignoring others (Shackley and Wynne, 1996). This process of uncertainty work has allowed medicine to claim authority over the condition in the absence of any concrete consensus about its nature (Seear, 2014; Whelan, 2007). As Seear has suggested, the naming and classification of a disease is a political act; creating theories about it materializes it as a distinct and biomedically knowable entity (Seear, 2014).

Significantly, for the theorization of ignorance, endometriosis is a phenomenon which has come to be defined by a lack of scientific knowledge and consensus. The ambiguity that exists around it has become the defining feature of the condition, folded into scientific consensus statements and treatment schemas. Thinking about endometriosis as an indeterminate entity therefore illustrates how uncertainty around the condition is materialized via scientific accounts of its form and existence (Hollin, 2017). The claiming of this (non)knowledge about the disease by scientists demonstrates how a description of endometriosis as enigmatic is performed as a characteristic of the disease itself, rather than a failure of science to fully comprehend its nature (Seear, 2014). It also illustrates how knowledge about endometriosis has been left unfunded, incomplete and undone, despite the growing existence of accounts from women about its devastating effects.

Women’s lived experience: pain, embodied knowledge and wilful ignorance

Historically speaking, endometriosis can be situated as part of a wider set of gendered omissions and assumptions about women’s bodies, psychological make up, and legitimacy as narrators of their own biographical experiences (Greenhalgh, 2001; Kempner, 2014). The association of

endometriosis with historically specific constructions of menstruation and women’s pain has informed contemporary imaginaries around the condition, including ideas about women being somehow accountable for their own illnesses. These silences have mediated contemporary classifications of the disease, which have been constrained in their ability to represent an embodied, lived experience of the condition. Attempts to stratify and categorize the condition have drawn criticism from feminist social scientists due to the lack of correspondence between classificatory categories and women’s lived experiences (Culley et al., 2013b; Denny, 2004b; Seear, 2014; Whelan, 2007; Young et al., 2019). As existing classificatory systems for endometriosis focus on surgical diagnosis, they have systematically ignored women’s embodied symptoms and are therefore often in conflict with women’s realities. This absence is reflective of how the undone science of endometriosis has operated to exclude women from the agenda-setting process, and how the spaces where knowledge could empower marginalized social groups (Hess, 2007) are contoured along existing axes of power. The struggle for women to have their experiences legitimated via, or in spite of, medical categorization has also been the focus of feminist and social science research, with this work consistently demonstrating that women feel they are disbelieved or ignored when they present with symptoms of endometriosis in primary care (Culley et al., 2013b; Denny, 2004a; Seear, 2009a, 2014; Whelan, 2007; Young et al., 2019).

One of the most common symptoms of endometriosis is chronic pelvic pain. Scholarship on the sociology of pain demonstrates how an experience with no identifiable pathology does not fit easily within the biomedical health/illness dichotomy (Grace and MacBride-Stewart, 2007; Greenhalgh, 2001), and that pelvic pain is liminal due to its correlation with menstruation fertility and sexual health. In the case of endometriosis, this has materialized in the absence of women’s experiences of pain being used to inform medical classification systems. However, women’s accounts repeatedly demonstrate the considerable impact of pain on their day-to-day lives (Denny, 2004b; Seear, 2014). This scholarship highlights the severity of the condition when women’s embodied lived experiences are acknowledged. However, instead, in the context of undone science, pelvic pain becomes a liminal subjective experience which is wilfully ignored in the development of formal definitions (Grace and MacBride-Stewart, 2007; Whelan, 2007). Painful sex (dyspareunia) caused by endometriosis is even more shrouded in silence as studies indicate that women do not feel able to discuss this symptom with healthcare professionals, are embarrassed or ashamed (Culley et al., 2013a, Denny, 2004a), or their experiences are dismissed when they do try to discuss the issue. Pain recognition is particularly problematic for minoritized women, as evidence demonstrates they tend to be treated as less reliable narrators of experiences of pain than white women by clinicians (Bowler, 1993; Denny et al., 2010). The related silencing of the experiences of Black and minority ethnic women with the condition has added to the misperception of endometriosis as a white career woman’s illness (Seear, 2014).

Research with women also illustrates how their own authoritative knowledge of their bodies is undermined when

attempting to seek diagnosis, and specifically that their symptoms are not taken seriously in primary care settings when they visit their general practitioner (GP) (Culley et al., 2013a,b). In a reflection of the historical treatment of women with gynaecological complaints, patients with endometriosis are considered to over-inflate or misattribute their symptoms (Whelan, 1997, 2003, 2007). This lack of recognition presents a barrier to preliminary treatments (such as pain relief and hormonal treatments), the possibility of a more definitive diagnosis via laparoscopy, and the potential for specialist surgical treatment options. However, this aspect may be shaped by local healthcare infrastructures. The way that care is organized at a national and local level means that access to medical management is variable and locally contingent. For example, in the UK, access to specialist tertiary care is via GPs, whose knowledge of endometriosis can be highly variable. Women in the UK have relatively limited scope to change their GP, and therefore can spend many years attempting to negotiate a diagnosis and access to treatment (Denny, 2004a). In the USA, in contrast, healthcare coverage is determined by an individual's access to medical insurance and is characterized by the availability of a varied and high number of healthcare providers and medical specialists, providing women in the USA with increased opportunity to directly contract care from an endometriosis specialist than may be possible in other jurisdictions.

Scholars of medicalization and diagnosis have long demonstrated how the identification of a condition and the ability of patients to have their experiences labelled has a number of positive effects, including access to treatment, support, and social and biographical legitimation (Brown et al., 2011; Jutel, 2011; Latimer, 2000; Nettleton, 2004; Swallow, 2019). Brown et al. suggest 'the act of diagnosing an illness is important on multiple levels. It is about an individual's relationship to the illness or act of diagnosis, the collectivity of people who suffer from an illness, and the larger social structures that influence the illness and its diagnosis' (Brown et al., 2011: 942). The lack of engagement with women and their experiences, especially in contexts where specialist care is subject to gate keeping, has meant that the prevalence and trajectory of a wider range of symptoms and their related biographical interruptions have not been accounted for adequately in surgical classificatory systems. This is especially true with regards to symptoms which are considered to be 'invisible', such as chronic pelvic pain.

Feminist standpoint theorists have drawn our attention to how the experiences and values of a group are ignored in the production of knowledge (Tuana, 2004). Women's health has become a key historical site for struggle over recognition and the creation of new spaces distinct from the 'willful ignorance' of androcentric epistemologies (Tuana, 2004, 2006; Whelan, 2007). A sustained lack of scientific and policy attention to what is a gendered condition can therefore be seen as part of a historical process of systematic exclusion. Emma Whelan uses the notion of 'epistemological purgatory' in order to illustrate how women are caught in a liminal space regarding the definition of their experiences and embodied knowledge about endometriosis in relation to 'expert' knowledge (Whelan, 2007). The wilful ignorance around women's lived experi-

ences of endometriosis and a long-standing silencing of their claims have shaped, and continue to shape, the ways in which the condition has come to be defined, indelibly marking it as a disease which is complex, difficult and enigmatic.

Endometriosis, health policy and the consequences of undone science

As an example of undone science, endometriosis illustrates how ignorance can shape the trajectory of the condition as well as its contemporary categorization and management. Given the science and policy blind spot around endometriosis, its impact on the healthcare system, social relations and the wider economy have gone largely ignored (As-Sanie et al., 2019; Simoens et al., 2012). Classed as 'women's troubles' or women's 'business' (terms which actively work to silence women's experiences in a very direct way), wider understanding about endometriosis has been limited to those with direct experience. Whilst this is beginning to shift in some contexts (mostly in high-income countries, and largely in relation to the experiences of white middle class women), this ignorance has important implications for those who live with the condition.

Endometriosis is often ignored as a public health priority. In the UK, clinical guidelines for the management of endometriosis were not published until 2017, and authors have noted that practice guidelines elsewhere have not been updated for 5–10 years (As-Sanie et al., 2019). Whilst the James Lind Alliance (a non-profit-making priority-setting initiative) in the UK set up a priority-setting partnership for endometriosis research in 2015, endometriosis is not listed as a research priority with the UK National Institute for Health Research or any other major funder. Whilst a focus on endometriosis would increase research and health service spending, it could save millions of pounds in lost productivity, not to mention the costs to individuals and their families (Simoens et al., 2012). Acknowledging that diagnoses are not prior ontological categories, acceptance and visibility of a disease entity provides 'substance around which support and interest can rally and a range of agendas be met' (Jutel, 2011: 142).

With this aim in mind, developments around what has been referred to as the 'menstrual equality movement' (Weiss-Wolf, 2017) have shone a light on endometriosis, nudging it ever further into the public arena and imagination. This movement has sought to bring menstrual experiences into the public domain, and to problematize their long-standing cultural and political invisibility. Within this context, endometriosis advocacy organizations and support associations (mainly in high-income contexts, e.g. UK, USA, Ireland, Australia) – which have taken a central role in drawing attention to the condition and needs of women in the absence of formalized attention and policy for many years – have grown more visible. Their work has largely revolved around women's situated experiences as a form of resistance to systematic and organizational ignorance about endometriosis. The development of global menstrual politics, which consider issues around period poverty, menstrual disorders and greater recognition of women's experiences of menopause, may be increasingly – finally –

challenging the long-standing silences, omissions and ignorance around women's menstrual biographies and offering some hope that a wider range of stakeholders may become enrolled in to the process of knowledge production, leading, ultimately, to a position where women's health is foregrounded. The existence of these groups, over many decades, raises questions about how far social movements need to go in order to redress the stubborn embeddedness of ignorance and the silencing of particular types of experience.

Conclusion

Endometriosis represents a rich example of the active production of ignorance due to its long-standing invisibility in biomedical, political and social contexts. In this sense, it shares characteristics with a number of other contested and invisible conditions in which science is left 'undone'. Applying an ignorance lens to the case of endometriosis adds further evidence of the ways in which women's experiences of illness have been, and continue to be, ignored. Scholars have illustrated how ignorance is not a motionless state but is an 'active accomplishment' (Gross and McGoey, 2015: 5) in which a range of stakeholders may participate in knowledge production, non-knowledge production and a range of ignorance practices. Drawing on this approach, this paper has demonstrated how the legacy of the invisibility of endometriosis shapes its place in the present political and social arena, and is reflective of a process of undone science.

Whilst social science and feminist research has drawn attention to the historical absences around endometriosis and the exclusion of women's accounts, more empirical work which explores the active construction of ignorance around endometriosis in contemporary healthcare and policy contexts is needed urgently, especially in low- and middle-income settings. The social and political significance of endometriosis as a chronic, life-limiting condition which affects millions of women globally continues to need attention, illumination and critique.

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