

THE LIBRESSE

PAIN REEP RPT

#PAINSTORIES AROUND THE WORLD  
FROM EXPERTS AND PATIENTS



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# 1. BACKGROUND



## The Libresse Project

Essity's #wombstories campaign has opened up representations and conversations around the rollercoaster women go through that are still experienced in silence. Part of the #wombstories launch invited women to share their experiences. Many women gave poignant testimonials of painful experiences that needed to be heard. It became clear that, from period pain to endometriosis, polycystic ovary syndrome, vaginismus, adenomyosis, fibroids, ovarian or cervical cancer, pain during and after birth, painful sex due to vaginal dryness around menopause and so many more experiences, there are so many sources of pain for women that are under-spoken about, under-listened to, under-estimated and/or under-diagnosed, with disastrous consequences for their physical and mental wellbeing.

What's more, when it comes to pain, the traditional system is often limited to a numerical scale of 1 to 10, whereas pain is by essence anumerical, too complex to rate and too elusive to describe. There is a lack of vocabulary and a lack of culture of analogies and metaphors to describe pain that means women aren't equipped with the right tools to be heard and supported.

This Libresse Pain project exists not only to give women's pelvic pain visibility and create an open culture of sharing, but to try and help towards better diagnosis and better support so no woman ever has to experience pain in silence and shame again.

## Report Objectives

This report collects women's stories and their subjective, visceral definitions of their pains in ways we've never heard before. It has three further objectives:

- To identify cultural codes and behaviours across markets on the subject of pain
- To interrogate the existing medical systems put in place to measure pain
- To help show how doctors and patients could benefit from the use of more honest, creative and empathetic language around pain

## Background to the research

**The report is based on findings from three stages of research that were conducted across six regions of the world:**

- Latin America (Colombia, Mexico and Argentina)
- Russia
- China
- Malaysia
- Middle East (Saudi Arabia and Jordan)
- Europe (UK, Sweden and France)

**The focus of the research was painful gynaecological conditions in the following order of priority:**

- Main priority: endometriosis, adenomyosis, fibroids
- Second priority: dyspareunia, vaginismus, pelvic inflammatory disease, ovarian cysts, vulvovaginal atrophy, vulvodynia
- Third priority: polycystic ovary syndrome (PCOS) and pre-

menstrual dysphoric disorder (PMDD) – typically less associated with physical pain.

## The three stages of research comprised:

### Stage 1: Desk research

**Stage 2: Qualitative research interviews with experts to understand the cultural context and codes. We interviewed 33 experts across the regions, including:**

- Seven senior gynaecologists
- Five gynaecologists / other experts in endometriosis
- Six sexual health experts, including sexologists, researchers and authors/advocates in the sex-positive movement
- Five psychologists psychoanalysts
- Three physiotherapists specialising in female pelvic pain
- Three semioticians
- Two experts in racial disparity
- One neurologist
- One general practitioner specialising in women's health

All experts interviewed were women or non-binary.

**Stage 3: 24 qualitative research interviews with women living with painful gynaecological conditions across the regions, some of whom had had taken on an advocacy role, including:**

- Nineteen women who had a single or comorbid diagnosis of endometriosis, adenomyosis, fibroids and ovarian cysts, plus dyspareunia

- Two had primary painful sex conditions: dyspareunia, vulvodynia
- Three had other conditions including polycystic ovary syndrome (PCOS), pelvic inflammatory disease and pre menstrual dysphoric disorder (PMDD)

Running the global project, moderation in English and analysis were the responsibility of Steven Lacey and Zoë McQuillin of The Outsiders.

Non-English moderation of interviews and additional input was conducted by:

- Tatiana Dvenadtsatova, Salt Research, Russia
- Vanessa Vallenilla, Latin America
- Shaghaf Abusamra and Maha Dabbour, Insider KSA, Middle East
- Felicia Schwartz and Rachel Wang, China Insights, China and Malaysia

Recruitment of participants in the UK, France, Sweden and Latin America was conducted by Leftfield.

## 2. A NOTE ON LANGUAGE






Ingrained gender bias stops women getting the treatment they deserve. But painful conditions affect trans men and non-binary people, too. As does bias.

As a brand, we offer products for anyone who needs them, regardless of how they may identify. And when it comes to language, we are committed to being as inclusive as possible, but appreciate that there are many views that cannot currently be expressed by a common language and we may not get it right for everyone, all the time. We are learning every day.

We have kept the language in this report as inclusive as possible. Some of the research we have quoted did not distinguish on the basis of gender identity and the use of the term 'women' throughout reflects this.

### 3. ACKNOWLEDGEMENTS





We would like to thank the experts who provided us with such valuable insights, and Hannah Marcus and Abigail Mlinar for their input on the findings.

In particular we would like to thank the women who took part in the interviews and shared their, often harrowing, stories of pain so candidly and courageously.

All women's names and any identifying information have been changed throughout this report to protect their privacy

## 4. GYNAECOLOGICAL PAIN CONDITIONS: STATISTICS AND FACTS



***"If all the estimated 180 million women with endometriosis formed their own country, it would be the 8th largest nation, bigger than Russia."*** Shannon Cohn, TEDx Speaker

Gynaecological pain conditions are widespread and their impact is far-reaching.

## Endometriosis

Endometriosis affects an estimated 1 in 10 womb bearers during their reproductive years.<sup>1</sup> In the UK, it affects 1.5 million women - a similar number of women affected by diabetes.<sup>2</sup>

A research study across ten countries in 2013<sup>3</sup> found that, despite treatment:

- 59% of women with endometriosis continued to have painful periods (dysmenorrhea).
- 56% continued to have painful sex (dyspareunia), of which 80% had to alter their sexual behaviour in terms of interrupting or avoiding intercourse due to pain.
- 60% continued to have chronic pelvic pain.

Endometriosis affects both adults and adolescents. A US study showed that 45% of adolescent females with chronic pelvic pain were found to have endometriosis at laparoscopy.<sup>4</sup> There is a 10-fold increased incidence in women with an affected first-degree relative according to a familial association.<sup>5</sup>

It takes a long time to reach a diagnosis, and misdiagnosis is rife.

- According to the Global Study of Women's Health, conducted in ten countries, two thirds of women with endometriosis first sought help for their symptoms before the age of 30, with many experiencing symptoms from their first period. 65% of women with endometriosis presented with pain.<sup>6</sup>
- On average it takes 7.5 years from symptom onset to get a diagnosis.<sup>7</sup>
- A UK study showed that 58% of women in the UK had to visit their GP over ten times, and 32% of women found their gynaecologist either unhelpful or very unhelpful.<sup>8</sup>
- 68% of women with endometriosis in the UK were initially misdiagnosed with another condition.<sup>9</sup>

Endometriosis has a significant impact on fertility and child birth:

- 30-50% of women with endometriosis experience infertility<sup>10</sup>, and infertile women are 6 to 8 times more likely to have endometriosis than fertile women.<sup>11</sup>
- A Scottish research study<sup>12</sup> suggests the odds of an ectopic pregnancy are nearly trebled to 1.6% with endometriosis. The chance of miscarriage increases by 76%, a premature birth by 26% and the need for a caesarean section by 40%.

People with endometriosis are also more at risk of several diseases versus

the general public. Swedish research identified that<sup>13</sup>:

- The risk of ovarian cancer is 37% higher
- The risk of endocrine tumours is 38% higher
- The risk of kidney cancer is 26% higher
- The risk of thyroid cancer is 33% higher
- The risk of brain tumours is 27% higher
- The risk of malignant melanoma is 23% higher

According to the American College of Cardiology, a heart attack is 62% more likely.<sup>14</sup> There is a higher risk of breast cancer in women diagnosed with endometriosis after age 40, because of their increased exposure to elevated endogenous oestrogen.<sup>15</sup>

Aside from the physical impact, endometriosis affects all areas of life, including work/career, relationships, mental health and social life. According to Victoria Williams, in a study of 7,000 women across 52 countries:<sup>16</sup>

- Over 40% had given up or lost their job because of endometriosis.
- Women lose an average of 10.8 hours per week due to pain.
- Women lose an average of £5,757.72 per year due to lost work days.
- Many women suffer in silence in the workplace in order to protect their jobs and credibility.

In a 2020 UK survey of 10,000 women living with endometriosis:<sup>17</sup>

- 89% said it affected had a negative or very negative impact

on their ability to live their life as they wanted.

- 80.8% said it adversely affected their mental health.
- Only 16% said they felt in control of their daily lives.

Between January and October 2019, more than 100 women in the UK had taken their own lives due to endometriosis.<sup>18</sup>

The economic impact of endometriosis is huge. For example, it costs the UK economy £8.2bn a year in treatment, loss of work and healthcare costs.<sup>19</sup>

## Adenomyosis

*"We're in a period of time where we're recognising that maybe it's more common than we thought. We're still in the area where things are evolving in regards to diagnosis, what it causes, and what you should do to treat it."* Dr. Cynthia Austin, obstetrician-gynaecologist, Cleveland Clinic, Ohio<sup>20</sup>

Adenomyosis is a poorly understood condition - reliable data on the population-based incidence of adenomyosis does not exist.<sup>21</sup> Adenomyosis is often under-diagnosed. Until relatively recently, diagnosis was only possible on histologic examination of a uterus following a hysterectomy. Transvaginal ultrasound and MRI can now help to diagnose it.<sup>22</sup>

- The NHS estimates that around 1 in 10 women have adenomyosis, but around one third may not have symptoms.<sup>23</sup>
- A UK study suggests that around 21% of symptomatic women attending gynaecology clinics have adenomyosis,

diagnosed by transvaginal ultrasound, which increases to 32% for 40-49 year olds.<sup>24</sup>

- Adenomyosis often coexists with other gynaecological conditions, such as endometriosis (20-80% of women with endometriosis have adenomyosis) and uterine fibroids (15-57% of women with adenomyosis also have fibroids).<sup>25</sup>

Adenomyosis has multiple symptoms and a high impact on women's lives:

- In a US study among women with adenomyosis, over fifty symptoms and thirty impacts were reported, and all women experienced multiple symptoms. The most common symptoms were heavy menstrual bleeding (87%), cramps (84%), and blood clots during menstrual bleeding (84%). The most common impacts were burdensome self-care hygiene (71%), and fatigue/low energy (71%) and leisure/social activities.<sup>26</sup> The authors noted:

*"A literature search revealed a limited understanding of the signs, symptoms, and impacts of the condition, with little evidence derived directly from women with adenomyosis. To improve management of adenomyosis, it is important to understand the experiences of women with this condition."*

Adenomyosis is linked with infertility:

A Spanish study of women having fertility treatment showed adenomyosis prevalence in 24.4% of women aged at least 40 years old and 22% in women less than 40 years old. This increased to 38.2% in cases of

recurrent pregnancy loss and to 34.7% in previous fertility treatment failure.<sup>27</sup>

## Fibroids

Fibroids are a very common condition. Around 1 in 3 women will be affected by fibroids at some point in their lives.<sup>28</sup>

A UK survey of 2,600 women<sup>29</sup> found that time to diagnosis can be lengthy, and women are pushed towards accepting hysterectomy as a treatment option:

- 12% of women surveyed with fibroids took 1-2 years from their diagnosis to get their treatment.
- 70% of women were told about hysterectomy, however only 38% opted for this treatment.
- By contrast, the percentage of women told about other available treatments was much lower: 47% of women were told about myomectomy, 54% were told about Uterine Fibroid Embolisation, and few were told about pharmaceutical options.
- 43% of women were not satisfied with the information about their treatment choice.
- Over 20% of women sought a second opinion during their diagnosis and treatment.
- 34% of women were not satisfied with their treatment.

Fibroids have a negative impact in all areas of women's lives. A 2009 survey<sup>30</sup> of 1,533 women with a diagnosis across eight countries identified that:

- 53.7% of women reported that their symptoms had a negative

impact on their life in the last 12 months

- 14.8% said it had a severe impact
- 18.9% said it had a moderate impact

Of these women:

- 42.9% said it affected their sexual life
- 27.2% said it affected their performance at work
- 27.2% said it affected their relationship & family
- 24.4% said it affected their attendance at work or university
- 22.7% said it affected social activities
- 16% said it affected the type of clothes they chose to wear

The impact on fibroids on the economy is huge. US studies suggest lost work productivity potentially totals \$17.2 billion per annum<sup>31</sup>, and on average, the work performance of fibroid sufferers was impaired 18% of the time, compared to 8% for the control group.<sup>32</sup>

## Painful Sex (dyspareunia)

*"When it comes to 'good sex', women often mean without pain, men often mean they had orgasms."* Debby Herbenick, professor, Indiana University School of Public Health<sup>33</sup>

It is difficult to ascertain the incidence of dyspareunia (pain during sex) accurately, as the majority of cases are unreported<sup>34</sup>. Painful sex is associated with many conditions, for example:

- Vaginismus, vulvodynia, vulvovaginal atrophy, vulvovaginitis

- Endometriosis, adenomyosis and fibroids
- Ovarian cysts
- Pelvic inflammatory disease
- Vaginal infections and STIs
- Problems with the cervix
- Menopause
- Pregnancy / post-childbirth
- Lack of arousal and lubrication due to (for example), relationship problems, depression, tiredness and previous physical or mental trauma
- Allergies to spermicides and latex

Despite such a long list, more interest is paid to men's sexual health than women's. PubMed (a search engine accessing primarily the MEDLINE database of references and abstracts on life sciences and biomedical topics) has 393 clinical trials studying dyspareunia, 10 studying vaginismus and 43 studying vulvodynia. It has 1,954 studying erectile dysfunction.<sup>35</sup>

Women experience pain during sex at different stages of life for different reasons. For this reason, the American Gynecological Association estimates that up to 75% of women will experience it at some point.<sup>36</sup>

- According to the Sexual Advice Association in the UK, sexual problems affect around 1 in 3 young and middle-aged women, and around 1 in 2 older women.<sup>37</sup>
- 15% of women have chronic dyspareunia that is 'poorly understood, infrequently cured, often highly problematic, and distressing'.<sup>38</sup>
- The UK National Survey of Sexual Attitudes and Lifestyles found of those who reported painful sex (7.5%), a quarter had experienced symptoms frequently or every

- time they had had intercourse in the last six months or more.
- Around a third of these women said they were dissatisfied with their sex life, compared with one tenth of the women who didn't report painful sex.<sup>39</sup>
- The prevalence rate of vaginismus has been estimated as 5% to 17%, and it is thought to be one of the more prevalent female sexual dysfunctions.<sup>40</sup>
- It is estimated that half of all women older than 24 years will experience at least 1 episode of vulvovaginitis discomfort; however, some this may be an underestimate.<sup>41</sup>
- 8.3% of women in a test population experienced vulvodinia.<sup>42</sup>
- In an American study, vaginal discomfort related to menopausal changes caused 58% of women to avoid sex, with 59% finding sex painful.<sup>43</sup>
- A cross-sectional study on the effects of childbirth on sexual health reported that an estimated 17% to 36% of women reported dyspareunia at six months postpartum.<sup>44</sup> 24% of women reporting dyspareunia at 18 months postpartum.<sup>45</sup>

Women tend not to seek help for painful sex. American research showed that only 15% of women who had postnatal dyspareunia (pain during sex) discussed it with a health provider.<sup>46</sup>

A Swedish study<sup>47</sup> showed that a significantly higher proportion of young women who continue to have vaginal intercourse despite experiencing pain versus those who did not:

- Had difficulty refusing sex when their partner wanted it
- Felt inferior to their partner during sex
- Regarded their partner's satisfaction as more important than their own
- Felt dissatisfaction with their sex life
- Feigned enjoyment despite pain

42% of the young women interviewed said they didn't want to ruin sex for their partner, 41% said they felt foolish to interrupt, and 39% didn't want to hurt their partner by interrupting. 22% of women said they feigned enjoyment as it was important to be seen as the 'ideal sexual partner'. The study found that, for these young women, pain thus became normalised as part of sexual intercourse.

However, painful sex can mean that women do interrupt, or avoid sex. In an American study, 48% of women who suffer from painful sex reported sexual dysfunction and decreased sexual frequency.<sup>48</sup> Of the 1,708 women in the UK National Survey of Sexual Attitudes and Lifestyles study who were not sexually active, 2.05% said they avoided intercourse due to painful sex or a fear of feeling pain.

## 5. BARRIERS TO SEEKING HELP



There are many barriers to women seeking help for their gynaecological pain.

## I. Society has normalised women's pain

From periods to childbirth, women's pain is seen to be 'natural' and expected. This belief permeates society and is reinforced.

*"I was 17 years old. I developed at 13, and at 17 I already had very intense pain. What is seen as normal, here, to this day, people continue to say that this is normal, despite that the woman was created to menstruate, we are still being told these pains are normal".* (Person with endometriosis, Argentina)

*"This is something that's really key around this type of pain, that as women, or non-binary people with wombs, we're taught to believe that 'pain is normal;' 'you get pain every month', that's just what you expect, like 'sex might be painful', that's how it is, and I understand why people don't go to the doctors."* (Person with endometriosis, UK)

Women themselves believe it, and report that family members, friends, partners - and even some in the medical profession - believe it. Conditions like endometriosis are known to affect generations within a family, but may be undiagnosed, which contributes to the normalisation of pain, passed down from mother to daughter. Often women internalise these societal perceptions and dismiss their own pain, either deciding not to seek help, or delaying it and worrying they're 'making a fuss'.

*"Women are always telling me, 'Pain is normal!' I tell always say, 'It might be common but it's abnormal, definitely abnormal, pain is never normal.'"* (Gynaecologist, China)

*"We believe there's a delay because women think the pain is normal, 'My mother and my grandmother had the same problem' and, of course, you're at much higher risk of endometriosis if your female family members have it."* (Person with endometriosis, Sweden)

*"Your mother would say it is normal to experience pain during your period, the grandmother would say the same, the doctor too."* (Endometriosis Specialist, France)

*"Often it's quite hereditary too; for example, if you had a mother who had a lot of menstrual pain and your child has menstrual pain, it's like, 'Oh, I had this too, don't worry about it.'"* (Gynaecologist, Russia)

*"My mum's answer was that when I got to be a mum, pains will go away because that is what happened with her."* (Person with endometriosis, Argentina)

There is lack of education about female pain conditions - women have not been taught that their pain is real and valid. Often, excruciating pain is explained away as menstrual pain, even within institutions that should be taking care of women, for example school nurses who give out painkillers, and play down the importance of the frequency they are needed.

*"Oh, this is the way it's supposed to be, it's normal to bleed this much', 'It's normal to have menstrual pain, everybody knows about menstrual*

*pain', I say, 'Well, curling up for two days a month, lying on the floor, not being able to go to work, that's not normal', 'Oh, it isn't? Isn't it normal?'"* (Gynaecologist, Russia)

*"It's quite common knowledge that women have period pains, 'Everybody has it, everybody bleeds a lot.' I think one problem today is that many young girls have very little knowledge about their bodies. Many years ago, when you lived closer, perhaps, to another generation, you might have had a grandmother who was very interested in you and could tell you it wasn't normal."* (Person with endometriosis, Sweden)

*"In school, if a girl comes to you to get painkillers every month, it's like, 'Oh, well, menstrual pain is not so bad' and in school maybe they don't notice how this girl is often sick once a month, or in work places, people don't notice. So it's kind of normal."* (Person with endometriosis, Russia)

The ready availability of OTC painkillers can exacerbate the normalisation of pain - if a remedy is available without prescription, women may conclude that perhaps the pain/condition is not bad enough that they need help from the doctor.

*"If you've got an infection, you can't just go into Boots and buy antibiotics, you have to go and see a doctor about it but pain, we can buy a whole array of painkillers within a five-minute walk of the majority of houses, it's not a problem at all and so, therefore, it's easy to dose yourself up and then you start to become more used to what is normal."* (Senior Pelvic Health Physiotherapist, UK)

## II. Societal belief that women must endure pain

Aligned to the belief that pain is normal is the attitude that women must endure their pain. There is a push from society for women to 'just get on with it' - keep the pain to themselves and not bother anyone else with it. As a result, women suffer in silence.

*"Women either self-censoring, they don't want to attract attention to themselves, be considered a 'weakling' etc. So, women minimise what they are going through."* (Person with endometriosis, France)

Leftover perceptions of women being 'hysterical' regarding their pain means those who complain run the risk of being branded untrustworthy and irrational. There is a pain gap between men and women: women are far more likely to have physical pain misdiagnosed as a psychiatric condition.<sup>49 50</sup>

*"There is a tendency to devalue women's experiences, states, and feelings. It seems to us that she is hysterical, she dramatises, she comes up with, figured out for herself that she needs to endure."* (Person with adenomyosis & endometriosis, Russia)

*"People have the general idea that female patients are more dramatic."* (GP specialising in women's conditions, Malaysia)

## III. Cultural beliefs aligning endurance of pain with strength

In some countries/regions, such as France, Latin America and Russia, bearing pain is considered the woman's role. Stoicism can be seen as

admirable and may be a source of pride.

*"Pain or suffering still is seen as a 'woman's lot' in certain areas. Expressions like 'you have to suffer to be beautiful' and a number of demeaning expressions for women who are 'weaklings', i.e. complain about pain (douillettes, femmelettes, chochottes)." (Person with adenomyosis & endometriosis, France)*

*"I think it is customary for Russian women to stand pain... 'It hurts. Yes, everyone has something that hurts' ... Who is Russian woman? 'She stops a galloping horse, goes into a hot bath', this image has nothing to do with reverent attitude towards your body, towards pain, they are not in line with it. 'You are for keeping nose to the grindstone...' The Soviet and post-Soviet understanding that you should be a healthy woman whose duties are to feed everyone, dress, get hammered, put a drunk husband to bed, and solve all other problems." (Person with adenomyosis & endometriosis, Russia)*

#### **IV. Lack of support from others in their lives**

Some of the women we spoke to felt able to open up to family, close friends and their partners about their pain. Some of these found them to be supportive.

*"When I talked to my friends, and I feel better." (Person with adenomyosis & endometriosis, Russia)*

*"To make me happy, they [friends] would also go out and sing Karaoke with me, go jogging, mountain climbing, anyway. I took time off. It*

*feels so good to chat with my friends. At that time, my relationship with my husband was not very good." (Person with adenomyosis & Endometriosis, Mexico)*

However, others felt unable to talk to anyone – or if they did, found a lack of support from friends, family and/or partners, or even that they blamed them.

*"I was so shy so I didn't tell my mum, I only visited the doctor after I got married." (Person with endometriosis, Saudi Arabia)*

*"My sister felt discomfort, but neither of them named disabling pain, neither of them. [Yet] I was the weak one [in the family] and she was the strong one. It was like that." (Person with endometriosis, Argentina)*

*"My husband...when I told him (that I'm in pain), he would only say that you don't need to tell me so much about it. You can see a doctor, and I am not a doctor, how can I know how to help you?... I didn't dare to annoy him with my negative feelings. All I can do is take good care of myself and get better as soon as possible." (Person with Adenomyosis & Endometriosis, China)*

*"My husband is not very good-tempered. He will get angry if I talk to him too much [about my pain]. I am afraid of him." (Person with adenomyosis, China)*

*"I once told my mum and she started shouting and was like, 'This is because you lend your clothes to your friends and you don't listen to me! One of your friends could suffer from inflammations and she must've*

*infected you! You don't listen to me!' So I didn't tell her anything anymore." (Person with endometriosis, Saudi Arabia)*

As a result, some kept their pain secret from partners and others in their lives.

*"The other day I was going out with my husband and we were in the car and it was a long drive. I felt that I needed to go to the toilet and it is hard for me to put pressure on myself to prevent urination. I kept reciting Quran to save me from the embarrassment all the way. He talked to me and asked me what's wrong with me but I did not tell him anything. No, I did not want to tell him. If I told him, he would say, 'You neglected it in the beginning' and would blame me." (Person with endometriosis, Saudi Arabia)*

Internalisation of society's perceptions of female pain and the pressure to endure can lead to other women being judgmental and unsupportive of those who have pain. This can again cause women to question whether their pain is valid.

*"Not all women have painful periods, so you hear women saying, 'Well I have periods too, why is she making such a big deal?'...so in this misogynistic and patriarchal society, women are set against each other so you don't even have solidarity...there is always another women to discredit you and say 'What she says is nonsense'." (Person with endometriosis, France)*

Although it should be noted that women in online communities, in particular, are increasingly a source of support for women in pain, and give

them the confidence to seek help. The anonymity aids disclosure.

#### **V. Cyclical rather than continual nature of pain means it may be compartmentalised**

For some women, the worst pain is mainly experienced for a few days a month, during their periods. While the pain is incapacitating during this time, once it eases, they carry on with their often very busy lives, and delay seeing a doctor.

*"Things like endometriosis, because they're cyclical, I think a lot of women get past that bad few days and then it's all gone and so they carry on their lives and then the next one hits and so, especially if you're busy, you're preoccupied, you've got kids, you're working, it's very easy to just keep putting it off, and it's very hard to get to a doctor as well these days." (Senior Pelvic Health Physiotherapist, UK)*

#### **VI. Anxieties regarding the clinical consultation**

Concerns about the appointment with the doctor are multi-faceted:

##### **Embarrassment to discuss reproductive system pain and anatomy**

Some women reason that doctors are professionals and they feel reasonably comfortable discussing their pain with them. However, others find it embarrassing to discuss pain in what is considered a private part of the body. They may feel self-conscious talking about their anatomy (e.g. using the word 'vagina') with a doctor, or talking explicitly about their periods.

*"It's not like diabetes, it's a subject that makes people embarrassed to speak about it."* (Person with PCOS, Mexico)

*"I'm quite a confident person, so I was quite surprised that actually talking about feminine issues, suddenly I became a lot quieter, which is odd because I've had male doctors before, talking about other things, and it wasn't an issue but when I started to talk about my cycle and things like that, it was a little bit more uncomfortable."* (Person with fibroids, UK)

*"For teen patients it may be harder to express, the office environment is uncomfortable. For adult ones, that have already given labour, etc. they feel more comfortable. For men is usually more uncomfortable. For older women, privacy is more important, so there are some barriers, culturally, when the conversation is about the pelvis."* (Physiotherapist, Argentina)

### **Embarrassment and fear of being examined**

Some women, especially younger and those who have never given birth, feel concerned about undressing and being examined by a doctor. Internal examinations also create fear, both in terms of a lack of dignity and the potential pain.

*"There are people who especially are reluctant to being examined. So finally, some people just avoid seeing the doctor."* (Person with endometriosis, France)

*"They're afraid of the investigations with the doctor, lying in the chair and things like that, it's not a very nice thing to do and very young women*

*might be hesitant."* (Person with endometriosis, Sweden)

### **Anxiety of receiving medical results**

There is a fear of hearing 'bad news', for example finding out they have cancer. Some women prefer to remain in ignorance.

*"I think pain is quite scary to a lot of people because people are worried that it could be anything, people expect the worst... What if they tell me something awful?', it's the 'What if?'"* (Person with endometriosis & ovarian cyst, UK)

### **VII. Workplace discrimination**

Some women describe how a gynaecological pain condition diagnosis is not viewed sympathetically within their workplace. Time legitimately taken off from work is viewed negatively both by managers and colleagues, and their sickness record is held against them. As a consequence, they often struggle through, trying not to show they are in pain.

A participant in research conducted by the UK House of Commons Digital Engagement Team said:<sup>51</sup>

*"I have to force myself to work even when the pain makes me vomit. If I go off sick again, I know they will sack me, this has been made very clear. I work for HMRC and I know this is a massive issue for other members of staff as well."*

*"My last workplace bullied me and mocked my illness, nothing was done via HR and I was made to leave*

*instead. I have never had support from any workplace."*

*The truth, however, is that a whole host of employers are completely unsympathetic to the disease, and often dismiss employees because of a 'poor sick record'."*

### **Barriers to seeking help for painful sex (dyspareunia)**

Painful sex can present as a symptom of other gynaecological pain conditions such as endometriosis, adenomyosis, ovarian cysts and fibroids, as well as a standalone condition (e.g. vaginismus, vulvodynia). Our research indicates that women who experience painful sex are reticent to seek help, and even those who seek help for other conditions such as endometriosis, adenomyosis (etc.) find it difficult to mention their painful sex symptoms.

To understand why this is an area of silence, we need to understand the cultural context of sex. Painful sex experiences are embedded within societal beliefs and expectations regarding sex and sexual pleasure, which inform how women should 'perform' their sexuality. To greater or lesser degrees across the countries in which we conducted the research, three interconnected issues exist which impact upon women's propensity to seek help from doctors:

- There is shame regarding sex / sexuality
- Women's sexual pleasure is still not considered as important as men's
- Many women are not aware that painful sex is not normal

### **Elements of shame regarding sex are pervasive across all countries.**

This may be regarding sexual orientation and behaviour, and in some countries, women having sex before marriage. Sex is an area of silence and taboo. It is not publicly discussed. While some women in more progressive countries may discuss sex with close friends, dyspareunia is one topic that is largely kept secret.

*"Sometimes my friends come to ask me because they suspect that they have endometriosis...so they come to ask me or a friend's sister might suffer from endometriosis. I tell them about my pain, but I never tell them about my sex life."* (Person with adenomyosis, China)

*"They also know that you cannot talk about it with everyone, because they start criticising you and they start judging you, and, even though you are super prepared, the fear of being judged or the fear of being pointed at, is still being present with the woman, no matter how open she claims to be, no matter how liberal she feels, she has fear of being judged and the 'What will they say?'"* (Gynaecologist, Colombia)

*"Women may feel okay talking about the phase after the period...but when it comes to anything like sexual desire they'll avoid it, they wouldn't dare to talk about it, I can tell you. The majority will not be open to talk about it and in the rural areas there'll be zero chance of people talking about it."* (Person with ovarian cyst, Malaysia)

Society is also responsible for policing what 'good sex' is and how it is done, and what makes a woman 'sexy'. This generates feelings of shame, and

women can worry about the size, smell and shape of their body, which can affect levels of arousal. Women who have painful sex often feel resultant shame about disappointing a partner.

*"There's just so many things that we're led to believe about sex, what sex should look like, and so when you don't feel like you measure up to that, or you're not having the kind of sex that you see on television...then you feel, 'It must be me, I'm the thing that isn't quite right.'"* (Person with dyspareunia, UK)

*"Lots of people have painful sex because they feel like they're too hairy or 'it doesn't look nice'."* (Person with dyspareunia, UK)

Although the sex-positive movement is working hard to counter this, and change is taking place, a gender gap exists. Historically the focus has been on women upholding morality in terms of their sexual behaviour and men receiving sexual satisfaction. Women's sexual pleasure is (still) not considered as important as men's.

*"There is a gender gap in Russia now in the context of sex between a man and a woman, well, that a man should have 100% pleasure, and a woman...they don't think too much about women."* (Sex-positive coach, writer, Russia)

*"Even in social media where I have been blocked several times by the platforms themselves... they see it as a taboo when you speak about the female orgasm, or female sexual desire, female satisfaction, it is still seen as a taboo - and the woman herself says 'No. I better not go. I will stay like this. In any case he is satisfied.' They look*

*for the satisfaction of the man more than themselves."* (Gynaecologist, Colombia)

As a result, some women have never experienced any pleasure from sex, nor an orgasm – and some women do not know they exist. In fact, all that some women feel is pain.

*"Still some [women] do not know what an orgasm is."* (Sex-positive coach, writer, Russia)

*"I had a part in that book where I told my story....I said 'Wow! If this is pleasure, for me it is not it.'...I wrote: 'Is this what couples like? Is this feeling pleasure?' I mean for me it is not".* (Person with endometriosis, Argentina)

In Latin America, for example, women are discouraged from asking for what they need during sex. They are expected to be passive recipients.

*"When women are proactive in bed and take the lead and they tell their partner 'I want to do this or that, or I don't want to do that', it's not well taken."* (Sexologist, Colombia)

*"There are very few men that truly ask 'Do you like it? Are you ok? Are you feeling comfortable? Does it hurt?' Few men actually do it. They want to come, they want to enjoy it, and are not worried if the woman is enjoying it or not."* (Gynaecologist, Colombia)

Alongside this, sex education in schools (when provided) is poor. It focuses on the mechanics and does not broach pleasure. At most, it teaches young people how to avoid harm in terms of unwanted pregnancy and STIs – it is fear-led. This can leave some young women unaware that sex

can be pleasurable. There is also a lack of knowledge regarding the importance of arousal, in particular, and natural or product lubrication being necessary for comfortable sex.

*"You'd be surprised, some people don't even know that condoms exist or that there's a method called the 'withdrawal method', there are so many things. Over the last 2-3 years the Ministry has been trying to make sex education more accessible to everybody but it's still new and everything takes time."* (GP specialising in women's conditions, Malaysia)

*"There still is a lot of suspicion, apprehension, regarding sex education. When we talk about eroticism, or pleasure, when we talk about sexual response, when we talk about sexual diversity. Schools they continue to give talks about preventing pregnancies, preventing infections, or how to wear a condom and how to use a condom. So, basically, the schools do not want to talk to children about orgasm and pleasure."* (Sexologist, Colombia)

*"Sex education doesn't mention pleasure at all, I don't think I knew about it really, so I don't think it was built into my expectations of sex, people said it felt 'nice' but I didn't really understand what that meant."* (Person with dyspareunia, UK)

*"It isn't something that women grow up knowing that they need to be prioritising lubrication in order to experience pleasure and so they assume that they're also supposed to be well-lubricated and if they're not they think there's something wrong with them."* (Sex-positive coach, writer, UK)

**These three issues intertwine to create barriers to seeking help for dyspareunia:**

### **I. Assumption that painful sex is normal:**

Some women are not aware that sex is not meant to be painful. The myth that first-time sex is always painful also primes women to assume sex will be painful and it can become a vicious circle. This is exacerbated by the focus on penile-vaginal sex as the norm and ideal, which means that women persevere rather than seeking other ways of pleasure. Painful sex is also more likely to occur if women do not understand the importance (or existence) of arousal/lubrication and the focus is on male pleasure. This assumption that painful sex is normal means that women do not seek help from the doctor.

*"Sometimes I get the feeling that some women do not understand that it is not supposed to be painful, you don't have to have pain while you are having intercourse. I think some of this is cultural."* (Physiotherapist, Jordan)

*"I did suffer from pains but I thought that this was normal because I was still new with marriage, I used to ache during sexual intercourse."* (Person with endometriosis, Saudi Arabia)

*"Dominant culture will talk a lot about penetrative sex as being the baseline, what 'normal' sex is...if that's what people are always taught about or it's framed as that's what sex is, people are going to assume that that's the only thing they should do in order to experience sex and so if penetrative sex is painful for you, which it is for a lot of women with sexual health issues,*

they think that they can't have sex at all." (Sex-positive coach, writer, UK)

"Women are almost told that it's going to hurt from the first time you have sex, you expect losing your virginity to be painful. It doesn't have to be painful, you don't even have to bleed...I think then there's this sense that if women start having sex and it's painful, they're like, 'Oh, but it's always going to be a bit painful' or that's what's going to happen or whatever.'" (Qualitative researcher with expertise in sexual health/tech, UK)

- **Culture's focus on male pleasure leads to women feeling self-indulgent for seeking help:**

Women expect doctors to be dismissive of their request for help as they believe they view their pleasure to be irrelevant, and especially versus other patients' health problems.

"There is this idea that this topic is futile, that women don't really have a libido...There are these patriarchal clichés that men need it [sex] but women don't, so it's not a problem to give up one's sexual life or not have a fully-fledged sexual life because anyway it doesn't interest them." (Person with Endometriosis, France)

Women often blame themselves for experiencing painful sex, rather than believing it is a condition worthy of understanding, compassion and help.

Many women only approach a doctor for help regarding painful sex when it has become problematic for their male partner.

"They come when their partner expresses resentment or

disappointment in them. Most men don't understand that vaginismus is actually a medical issue... they just think their partner's being emotional, making a drama and all that... I'm actually surprised because women don't feel the need to fix the problem for themselves, it's mostly, 'I need to fix the problem because my husband is unhappy with me.'" (GP specialising in women's conditions, Malaysia)

- **Feel embarrassed or ashamed to discuss sex with the doctor:**

Many women do not broach the subject with their doctor out of a sense of embarrassment. They baulk at the thought of speaking explicitly about parts of the body or specific sexual activities that cause pain. There are taboos around naming the genitals and sexual terms.

"They don't address it as an issue, they don't know where to go to, because it's not a topic that's highlighted in Malaysia, I'll tell you that, the whole taboo about it is that people are just very shy to talk about sex – sex is not something that's spoken about, especially in the Asian countries – so that's their limitation." (GP specialising in women's conditions, Malaysia)

"They are embarrassed to talk with their primary care physician, they are embarrassed to talk with their gynaecologist, they don't even know how to bring up the topic to their doctor, so some keep quiet for years and years". (Sexologist, Colombia)

"I believe that 1 or 2 women out of 10 will tell me naturally, but for the rest you need to ask them intentionally. You have to ask them: 'How frequently do you have sexual relations? What type

of sexual relations do you have?'... I think that it is more shame and I think it is more taboo, definitely." (Gynaecologist, Colombia)

- **Unable to attend consultations alone (especially Latin America and Middle East)**

In some instances, the male partner may insist on attending the consultation too, and speaking for the woman. She therefore has no way of conveying her truth regarding sex / pain to the gynaecologist, unless the doctor insists on seeing her alone.

"When here, in the first meeting that we are having and when the man is present, the majority of times it is the man the one that answers... The man, always, always tells you everything is perfect. "No, she enjoys it very well. We both enjoy it. We both have desires. We both have satisfaction. We have sexual relations two or three times per week." I turn to the woman and she is serious. She does not even nod with the head... [whereas] When we go in [to a private room] and we are now alone, it is when she tells me "No. I do not feel anything. I do not enjoy it. It is not true, if anything we have sex once a week or once every fifteen days, and I do not like it. More than pleasure I feel pain, I feel a nuisance. I do not feel desire." (Gynaecologist, Colombia)

### **However, times are changing**

The picture is not all negative, however, as female sex-positive spaces are opening up, creating conversations about women's sexuality and addressing shame. The Internet allows women to find information they would not previously have had access to,

which makes them realise they are not alone. This has led to advocates speaking out, bringing uncomfortable ('shameful') topics of conversation about women's sexual pleasure and bodies into the mainstream. Online communities are bringing women who experience dyspareunia together, they are sharing their stories, and beginning to understand they are not alone or to blame.

"I am in very much a sex-positive bubble; sexually I'm not crazy/wild but the communities that talk about sex, there's much more openness, so I feel very privileged to be in spaces where those conversations do happen and I think it must be really hard for some people." (Person with dyspareunia, UK)

"Since women have more access to the internet now, they read things or their partner looks for research, 'Look what you have is vaginismus'." (Sexologist, Colombia)

In the UK particularly, the idea of 'good sex' is slowly being broached within sex education.

"'Pleasure' has started to become a topic that schools are open to considering, in the UK more than elsewhere, so that's really cool but, historically, it hasn't been the case and so 'Pleasure', in the education system, is doubly fundamental for women's sexual pleasure because there's more to be aware of." (Sex-positive coach, writer, UK)

In terms of conditions such as endometriosis, women are also speaking out in some countries (e.g. UK, France, Sweden, Argentina). They are becoming involved in support groups that fight for women's rights in

the context of women's gynaecological pain, and they are educating those around them.

*"I had to train, to educate my family... my brothers..... I do not usually go alone [to doctor's appointments] because to me is also part of the education, the education of my partner regarding what happens to me."*  
(Person with endometriosis, adenomyosis & fibroids, Argentina)

*"In these years it has opened up very much. We started about 7 years ago with the women's group and after us, many other groups opened up in Argentina, which is truthfully great, because almost in every province there is a women's group in the, of three different denominations, but all that work for this, the broadcasting of endometriosis, right?"* (Person with endometriosis, adenomyosis & fibroids, Argentina)

But ultimately, women do not want to fight this fight alone.

*"I believe that for this to really reach to that point there has to be a political decision in each country of taking it as a real woman's problem... In schools, in what is sex education, also to include endometriosis in it, because when you start your sexual life and if you start having pains, well one pathology could be endometriosis. So, it is like a bigger apparatus is needed."* (Person with endometriosis, adenomyosis & fibroids, Argentina)

## 6. EXPERIENCES OF THE HEALTHCARE SYSTEM



Once women finally seek help, our research indicates that they often have mixed, or wholly negative, experiences during their healthcare journey.

Most of the women who participated in our research typically had to see several doctors over a long time period before finally getting a diagnosis, and longer still before receiving treatment that helped them. Seven key issues prevail:

## I. Time

Doctors typically have 10-15 minutes (at best) to see each patient. Women feel this does not provide enough time for them to broach their multiple symptoms, concerns and questions. They describe the appointments as rushed, with them not being able to discuss everything they wanted. It does not create the optimum space for women to share difficult information candidly.

*"She didn't have time to talk to me in detail. She just responded to me as I talked to her. She only asked a few questions - how much was your menstrual flow, how many days was the menstrual period, and how painful it was. Then she touched my abdomen...asked me whether it hurts here or there... It's almost impossible to talk to the doctor more because they are very busy."* (Person with adenomyosis, China)

*"There's no space in those meetings to have that kind of sharing; it's a short meeting and depending on who you get, it wasn't the best experience for me."* (Person with fibroids, UK)

Clinicians also describe feeling under pressure to get to the crux of the issue,

which means they cannot explore women's lived experiences in full.

*"GPs don't have the time, the average GP consultation is 7 minutes, I think it is, which is just really hard to put somebody at their ease and get down to those sorts of discussions."* (Senior Pelvic Health Physiotherapist, UK)

For women, this creates the sense of being on a conveyor belt, with patients seen as 'another person with x condition', rather than an individual with a cluster of unique presentations, feelings and needs.

*"You don't have time to express everything that you feel. I knew they had more patients waiting, they had given me the treatment, they explained what they had to explain and were ready to move on."* (Person with PCOS, Mexico)

*"I was following a specialist endometriosis doctor at a clinic for a day and there was a patient every 15 minutes - she told them all the same thing and drew the same sketch. it was like a factory production line."* (Endometriosis Specialist, France)

## II. Lack of empathy

The women we interviewed described a lack of empathy within many consultations. Clinicians used mechanical, jargonistic language and had a clinical, cold manner. They had their own agenda, rather than empathetically listening to their patients.

*"I saw many gynaecologists and some were cold, direct, not compassionate, not listening - you are considered a*

*case, a number."* (Person with endometriosis, France)

*"They lack that empathy, it's very mechanical, 'If you do this, this will happen, if you don't then this will happen'."* (Person with endometriosis, UK)

*"It wasn't lots of open questions, it was very clinical ... Devoid of empathy. I was having to ask [about] all the terminology that was in the report... 'What does that jargon actually mean?', it wasn't really explained for the lay person... It was very detached, unemotional and unempathetic."* (Person with fibroids, UK)

Often women felt the appointment focused on the clinician's perspective of the condition, rather than theirs. Women did not feel 'heard' or able to share their experiences. The care was often not collaborative. Doctors became annoyed if the woman had read up about conditions and were seen to know too much or challenge their opinion. They were chastised for asking too many questions, and felt like they were being a nuisance.

*"During that time, I wanted to ask her why I had this disease. She didn't answer and said why I had so many questions. All I need to is take the medication and follow her instruction."* (Person with adenomyosis, China)

Women felt treatments were recommended without much consideration for their needs or preferences, and discussion was discouraged. For example, women who had fibroids were often told only about hysterectomies, despite the availability of other treatment options,

and with no discussion regarding their desire to have children.

*"The medical establishment is not really tuned into listening to women...It is a prevalent culture of doctors who are always right and do not wish to listen to patients...they get annoyed when women arrive thinking they know a lot."* (Endometriosis Specialist, France)

*"Most doctors will not take the time to really ask questions. If one comes for the pill...they will not present the different types to give the woman an informed choice. The doctor will make the choices in their head...they make themselves a mental idea of what would be best without discussing this with the patient. They give no options. There is little discussion. The doctor is the one that "knows", the patients do not have access to this knowledge and find themselves almost dispossessed of their bodies."* (Person with endometriosis, France)

*"I tell you, you realise a lot of times that gynaecologists also don't want to battle anymore, they don't want to dedicate much time to the patients and they go the easy way, which is to perform surgery."* (Gynaecologist, Colombia)

Often women's concerns were treated without tact or compassion, for example women described being bluntly told they would never have children, without any preparation.

*"He asked me, "Why are you here?" I told him that I did a scan and I wanted to know the result. He asked me, "And why do you want to run this scan?" I told him because I want to get pregnant, so he looked at me and told me, "You will never be able to get*

*pregnant because you suffer from adhesions!" he spoke to me in a very rude and inappropriate way." (Person with endometriosis & ovarian cysts, Saudi Arabia)*

### III. Interfere in patient's social space

Women described clinicians transgressing boundaries and making inappropriate recommendations regarding their personal lives. For example, young women were told to become pregnant in order to overcome their pain or told to find a boyfriend.

*"I can recall their "golden words", how they told me that I would remain disabled if I did not have a child in the next six months... I was nineteen or twenty years old then, they told me to start planning a pregnancy. Yes, planning a pregnancy and enduring pain, because this is a woman's plight, it sounded like this." (Person with adenomyosis & endometriosis, Russia)*

*"He [gynaecologist] asked what kind of sport I do. I said that I go to the gym. He said, "Well, go, maybe you can find a guy there". That is, you constantly here inappropriate comments related to your appearance, sex life and health, they are never-ending...it's incredible." (Person with adenomyosis & endometriosis, Russia)*

### IV. Perceived knowledge gaps

Many women felt that clinicians did not know enough about women's pain conditions. Diagnosis times were very lengthy for many (up to eight years). Several of the women we spoke to received differing diagnoses along the way, histology test results and their interpretations were contradictory, and

doctors appeared bemused. Some were told the doctor could only guess what they might have. A few felt their clinician had little interest in their condition.

*"There's a big variation in knowledge and, perhaps, interest, which is the most important thing, from the doctors and nurses and everybody around." (Person with endometriosis, Sweden)*

*"...doctors very often try to get rid of such patients, not wanting to solve their problems, because, probably, because they cannot help, cannot help with their knowledge, their experience, have no idea how to treat such a patient, and what to do with her." (Person with adenomyosis & endometriosis, Russia)*

Women in the UK sometimes are not given access to specialist care, as GPs (the gatekeeper to hospital specialists) have varying knowledge regarding female pain conditions and may not refer on.

*"The problem with all of these things is that most women will go and see a GP first of all and the GP is a generalist." (Senior Pelvic Health Physiotherapist, UK)*

### V. Doctors reinforce society's perceptions that female pain is normal and women are 'hysterical'

Some doctors collude and reinforce society's beliefs that women's pain is to be expected and endured.

*"Some Chinese gynaecologists have a similar idea about pain, 'It's not a big pain, don't make a fuss, maybe just bear the pain.' I think doctors have a*

*role to play in educating patients about pain and emphasise that it's never worth bearing the pain and that it could be treated." (Gynaecologist, China)*

*"...they say, 'All women have pain, so try to bear the pain'. (Person with endometriosis, Saudi Arabia)*

*"...doctors say, 'Be patient, you are a woman, you have to endure, you have to be strong there'... I burst into tears when I left this doctor." (Person with adenomyosis & endometriosis, Russia)*

The stories women in our research shared bear out studies conducted over several decades: doctors sometimes psychologise women's pain, suggesting referrals to psychiatrists, rather than investigating the physical cause of pain.<sup>52</sup>

*"They would also send you to the psychologist, that happened to many of us. In fact, we do an event every year in March and we have a t-shirt that says 'I'm not crazy, I have endometriosis'. Many of us were sent to the psychologist like saying: 'Well, aren't you exaggerating?'" (Person with endometriosis, Argentina)*

*"If you hear stories from other women... generally they went through different specialists, and they even got sent to the psychologist for the issue of pain, and that the pain is normal and that you are imagining it, and that it is in your head." (Person with endometriosis, adenomyosis & Fibroids, Argentina)*

*"I think the great majority catalogues a woman like: "Pain? She must be depressed. She must have family issues. She has too much work." So, the*

*first thing they do, or the majority of what we do is to prescribe her an antidepressant to that woman. When you are not seeing the cause that is originating that pain, or you are not really paying attention to what that woman is telling you. That is precisely when these diseases prolong and that disgust or lack of trust with the gynaecologist or the doctor of that patient." (Gynaecologist, Colombia)*

There is a sense that some clinicians don't realise how incapacitating women's pain conditions are, and they downplay their importance and impact. By contrast, men's pain is taken far more seriously.

*"Those doctors don't think any of them [conditions] is a big problem." (Person with adenomyosis, China)*

*"The woman is placed as "Woman - Pain: She is crazy." Or "Woman - Pain: Depression." Or "Woman - Pain: She is calling for attention." And "Men - Pain: It is like more believable," because it is supposed that men complain less from pain than women. When the man complains about pain it is because he is really in pain, supposedly." (Gynaecologist, Colombia)*

Doctors often say, "Oh, endometriosis, everyone has it."...but not every woman has endometriosis-associated painful sensations, that is, this is also some physiological feature that does not apply to everyone." (Person with adenomyosis & endometriosis, Russia)

### VI. Red tape

Health service red tape creates problems for women in several of the countries explored.

In France and the UK, there can be a long wait to see a specialist – and in the UK the GP is the gatekeeper to this, so solely decides whether the patient's pain warrants further investigation (despite, as highlighted above, not always knowing much about women's pain conditions), unless the patient pays to see someone privately.

*"In this specialised endometriosis centre in Paris there is currently a 1 year waiting time for appointments."* (Endometriosis Specialist, France)

In Jordan, where medical insurance operates, referrals from the gynaecologist to other departments are not automatically covered, and interim steps are required which take time.

*"Insurance companies won't pay for physical therapy if the order comes from a gynaecologist. Once she sees a gynaecologist and the gynaecologist says "Yes, the physiotherapy would be helpful," then she has to go to an orthopaedic for a quick "what's your problem?", so they can give her the referral for the insurance."* (Physiotherapist, Jordan)

In China, the government determines how conditions must be diagnosed and which treatments can be offered to patients, so clinicians have limited options.

*"Government approves the book, in terms of how to make a diagnosis and give treatment, give the medicine for the specific symptoms, so they play by the rules and play by the book."* (Semiotician, China)

In the UK, women perceive different qualities of care and treatments offered on the NHS depending on the area/health Trust. This can also be a result of the need for the Trust to justify using a certain test or treatment.

*"...having moved to a different area throughout this period of care, the treatment that I've received, compared to where I originally was, has been really poor...I feel like I'm doing somebody else's job, whereas my friend, who remained in the same area and has a similar condition, although her endometriosis was much more severe than mine, her care's been brilliant."* (Person with endometriosis, UK)

*"When I went into one A&E visit...I said to the doctor, 'I need a laparoscopy, my endo's come back and it's really painful and I have these cysts that are contributing to the pain' and he said, 'We only do them as an emergency, if your temperature's normal, your vitals are normal, you're not vomiting, you don't have any other strange symptoms, so we can't justify that.'* (Person with endometriosis & ovarian cyst, UK)

## VII. Cost Considerations

Where women are self-funding, gynaecological care is expensive, and can be prohibitive.

*"It costs at least 70 EUR to see a gynaecologist, but only 23-27 EUR to see a generalist. Also, a GP can prescribe the pill – so some women make this shortcut."* (Person with endometriosis, France)

*"Yes, not everyone goes to see a gynaecologist. It is expensive, there are*

*not as many of them – and especially not of endometriosis specialist."* (Endometriosis Specialist, France)

## The Healthcare System: Painful Sex

Although some of the issues are similar to other female pain conditions, we will explore women's experiences of consulting clinicians regarding painful sex separately, as the cultural context of sex (i.e. shame plus the 'sex is not pleasurable or important for women' myth) has a further bearing on the doctor/patient consultation.

### I. Doctors can be dismissive of female sexual pain

Women's sexual pain is not considered to be worthy of discussion or help for some doctors. They are primed to help remove pain, but not in the context of improving pleasure. By contrast, however, male erectile dysfunction is taken very seriously by the medical profession, in fact, there are almost five times as many clinical trials on Pubmed about male sexual pleasure than about female sexual pain.<sup>53</sup>

*"...pleasure isn't a priority in medicine and it hasn't been historically and I still don't believe it is and frequently people's desires for good sex are ignored...the medical professional's obligation is to give them basic care and not help them thrive and I see that happening a lot, especially in women's sexual health issues."* (Sex-positive coach, writer, UK)

Women reported that it took them time to muster up the courage to speak to their doctor about painful sex, but they were dismissed.

*"I know that going to the doctor is dehumanising, which is a really strong word for it but there is this feeling of just like, 'Ah, I went to you about this really sensitive matter and you didn't take it seriously and I was really brave in coming and doing that.'" (Person with dyspareunia, UK)*

They shared anecdotes of doctors laughing at women and belittling their problem.

*"I did a lot of research about women's experiences of going to their GPs and some were laughed at and some were told, 'It will get better when you have children', I think one person got told, 'Having children will widen you out, so penetration will be much easier'."* (Person with dyspareunia, UK)

Women also report that doctors are more likely to take their condition more seriously if it is impacting on the pleasure of their male partner. This is a recurring theme – women are still often viewed in relational terms – whether as pleasure givers or providers of children for men – rather than as individuals who have a right to their own pleasure.

*"They often became more worried if it was affecting your partner as well, I think that was a really big thing, which, again, felt sexist...they always worried about how it was affecting the man and how that then impacted on the relationship, not, 'Oh, it's affecting you, how does that impact the relationship?' I think I had one who offered couple's therapy to talk about it but it felt so much like it was about the other person."* (Person with dyspareunia, UK)

## II. Clinicians tell women the pain is 'in their head'

Some painful sex conditions cannot be diagnosed by tests or linked to other pain conditions such as endometriosis. Women feel doctors convey the message that the pain therefore does not exist, they are imagining it.

*"Patients go years talking to general doctors, and not getting a diagnosis, getting tests that don't point to anything. Vulvodynia, for example, is not seen in tests...Patients say what they feel and are misunderstood. They need to be listened to and understood. And telling them 'it's in your head', it's terrible for patients."* (Physiotherapist, Argentina)

*"A lot of the time they're told it's in their heads."* (Qualitative researcher with expertise in sexual health/tech, UK)

## III. Clinicians are often out of their comfort zone

Female sexuality is not always included in the training curriculum. As a result, doctors can find it hard to discuss the subject.

*"This was a presentation I did at the last Sex Therapists Conference, I think Spain with Lilly Laboratories did this research. I think between 8% and 12% of the doctors ask their patient, be it man or woman, about their sexuality and their sexual relationship. Urologists only ask a man about his erection; they don't ask him about ejaculation or desire or about the patient's partner. So, it's a general taboo. But with women it's a more marked taboo because that veil of mystery and embarrassment that has to do with*

*women, and even healthcare professionals like doctors and psychologists, it's hard for them. Why? Because they still do not include in their curriculum a section on sex."* (Sexologist, Colombia)

Doctors may not always feel comfortable discussing painful sex and change the subject as a result, or dismiss the woman's concerns.

*"Depends on the age of the GP as to what they call it and what they think about it... And if a GP is not comfortable in discussing sex and problems around it then often these problems are quite dismissed... the conversations are really, really hard to have."* (Senior Pelvic Health Physiotherapist, UK)

*"They don't want to talk about sex, that's the whole thing, because they're embarrassed, they are, they're embarrassed!"* (Sexologist, Middle East)

Some clinicians make inappropriate comments. Some women advocates told us anecdotes of clinicians discussing the attractiveness of the patient's body, when they sought help regarding painful sex.

*"Some got comments about their pubic hair, I've definitely spoken to a few women like that, one said a nurse said she ought to shave her pubic hair."* (Person with dyspareunia, UK)

### • Some women have concerns regarding confidentiality and judgements

There is a concern, especially in more conservative cultures, that the doctor may judge their sexual behaviour. In

the Middle East particularly, it is a close-knit culture and women worry that what they say may get back to others in the community, leading to shame for their husband or judgement upon themselves, especially in terms of painful sex or conditions that cause infertility.

## Implications for women

As a result of these experiences, women report feeling dismissed, belittled and not believed. It serves to reinforce women's pain as irrelevant and women themselves as 'hysterical'. Women can even begin to question themselves and their judgement – wondering if it really is all 'in their minds'.

*"I think it's about not feeling listened to and not being believed."* (Person with endometriosis & ovarian cyst, UK)

*"Well, especially the doctors who tell you that 'This is all normal, do not pay attention, you are all right, there is nothing wrong with you'. You are always in such a cycle of good and evil, they tell you all the time that you are making it up and it does not really exist. And you yourself cannot get into your belly, and you think, 'Well, maybe you really make it up?'"* (Person with adenomyosis & endometriosis, Russia)

Women feel that their pain is minimised and pushed back to them – that they somehow lack resilience and need to 'toughen up'.

*"I would tell them that those were disabling pains. Some would minimise it by saying 'Well, that is common. Maybe your degree of pain tolerance is very low. Maybe the issue is that'."* (Person with endometriosis, Argentina)

In turn this leads to an (often long) fight to gain a diagnosis, where they may have to self-advocate and stand their ground.

*"A lot of the people I've spoken to, when they have gone to the doctors, you need to continually fight for what you believe or what you know to be going on with your body and that is the frustrating element of it, where you actually switch doctors or you go down certain routes which the doctor deems, 'Okay, we have to tick this box before we move onto this box' and that's what draws out the process."* (Person with endometriosis, UK)

Often, they are referred to different departments, hospitals or specialists throughout their protracted journey to diagnosis, where they have to explain their pain yet again to clinicians who may have contradictory opinions to the previous doctor. This can leave them feeling confused, despondent and exhausted.

*"You are sent from one office to another, you beat off the thresholds of hospitals, consulting rooms, and very often this affects your morale, because it is really hard, very difficult to exist, work, be in a family, and at the same time live through this circle - from one doctor to another doctor in different polyclinic and hospital departments."* (Person with adenomyosis & endometriosis, Russia)

Women's self-advocacy often has to extend to researching extensively and then fighting for treatments they want, as clinicians often don't mention all the treatments available and are seen to emphasise particular ones.

*"Many young people, myself included, do independent research, to be able to say, 'I've been researching this and I think maybe I'd like to try this' or, 'I've read about this and I'm a bit reticent because of xyz. Can you reassure me, can you explain?' I think the reason that I've got to the point now where I'm probably more vocal when I do see GPs, and I do ask more questions, and I know it's similar for friends, it's just we're tired of being messed about; you get to the point where you feel, 'I've been doing this for long enough and I just want some decent care, that's what I want and that's what I deserve' – right!?" (Person with endometriosis & ovarian cyst, UK)*

However, women do not always feel comfortable with self-advocacy or do not know where to begin. They may find the power dynamic intimidating, for example, and experience anxiety at the thought of challenging perceived authority, where clinicians have symbolic and cultural capital<sup>54</sup> and are resistant to 'share power'.<sup>55</sup>

Women are very relieved when they finally find a clinician who takes their pain seriously and wants to listen to them. Such doctors are often heard about 'on the grapevine' from other women, either friends or via online support groups and organisations.

*"I know that a lot of friends have experienced the general dismissive attitude and belittling and when you finally find someone who listens to you, it's kind of like, 'Alright, I need to stick with this doctor for as long as possible'." (Person with endometriosis & ovarian cyst, UK)*

*"A friend of my husband that was seeing that doctor... When I told her*

*what I had, she told me "Look, here this doctor is a specialist in endometriosis, why don't you go see him? Tell him you are going because of me." Honestly, he was excellent."*

(Person with endometriosis, adenomyosis & fibroids, Argentina)

However, a sense remains that women will unfortunately have to brace themselves to take on the medical profession, in order to disrupt the status quo and receive the help and treatment they need.

*"If you're not going to advocate for yourself then nothing will change. I don't want to paint the medical profession as unfeeling or uncaring because there are a lot of people who are very highly qualified and very responsive to patient care but in my experience and in the experience of the people that I've spoken with, it feels like they're diamonds in the rough and you really have to search and find the right person who will listen to you." (Person with endometriosis & ovarian cyst, UK)*

# 7. THE HEALTHCARE SYSTEM: MEASUREMENT OF PAIN



## Communication of pain

The International Association for the Study of Pain (IASP 1979) describes pain as:

*"An unpleasant sensory and emotional experience associated with actual or potential damage, or described in terms of such damage. Pain is always subjective. Each individual learns the application of the word through experiences relating to injury in early life."*

Aside from the impact of doctor/patient power imbalances and cultural codes that lead to assumptions regarding women's pain, pain is difficult to communicate. It is highly subjective. Inner pain is 'invisible' and it can be difficult to convey how it feels to others, or to get others to understand one's pain. This can lead to a feeling of isolation, described by Scarry (1985) as pain causing 'an absolute split between one's sense of one's own reality and the reality of other person'.<sup>56</sup> Women feel that doctors often do not seek to understand fully the pain they experience. Yet inadequate communication (and interpretation) has been described as one of the key contributors to poor or inadequate treatment of pain (Yates et al 2002<sup>57</sup>).

Our research indicates that no one technique to understand women's pain is used either across, or within, countries. However, the 1-10 quantifiable measurement of pain is prevalent.

*"I do use the measurement scale from 1-10 because it's a common system. I use it for every woman I see, just as a basic measurement of pain, because*

*the sensation of pain is different from one woman to another, and this measurement system is probably the most convenient one."* (Gynaecologist, China)

Clinicians can see some benefits of the 1-10 scale. It is generally considered easy for patients to understand conceptually, and can allow an understanding of the intensity of pain. It can be used to understand the trajectory of the condition and the impact of treatment. For those also working with the mechanics of the body, such as physiotherapists, it can be useful to determine how different movements affect the pain sensations, which indicates the impact on daily life.

*"I have actually found for my patients with pelvic pain that the 1 to 10 scale is helpful for them on like a session-by-session basis, you can see, 'Oh, when I came today it was 8 and when I am leaving it is 6'. In that sense it is beneficial".* (Physiotherapist, Jordan)

*"It can be used to evaluate pain in the same person from time to time. If somebody says they're in severe pain and then you give an intervention then afterwards you can say, 'Okay, but where are you now?' and you can see that it's lower, that's pretty good."* (Gynaecologist, Russia)

However, there are also disadvantages and limitations which have an impact upon women's ability to express their lived experience of pain in a way that makes sense for them. First, it is very subjective – one person's '6' may be another person's '9'. It also assumes that all patients are able to think numerically about their pain, whereas people organise their perceptions of

pain in different ways. Women can struggle to select a number and worry whether they are giving an accurate picture of their pain.

*"I would like to immediately identify the extremes... you hit your foot, but you still feel your body, something squeezed, you feel some discomfort. Is this already 1 or not yet? And what does 10 mean? You broke your leg and you lost consciousness from the shock or ... When are you being cut alive? ...If you have not experienced this maximum pain, conditionally, nobody extinguished cigarettes on you when you are getting acquainted with the pain scale, so you must somehow decide for yourself where you are on this scale... This is pretty strange to me."* (Person with adenomyosis & endometriosis, Russia)

*"Amanda Williams, who's at UCL, has done a lot of work showing that it doesn't work, that people don't tell you what you think they're telling you. If a clinician asks you to score your pain 0-10, a) you're assuming they have a numerical concept ... if you asked me, I might just say '3', I don't know, it's not my thing, I do words! ... so first of all you're assuming that, b) you're assuming that their pain goes up in incremental levels that are commensurate with the scale that you've presented them. (expert in racial disparity, UK)*

*"When I ask the patient, "From 1 to 10 how much pain do you have? 1 is no pain and 10 is extreme pain and we need to take you to the emergency room and even then they say "Ah, I do not really know". Even when you explain the 1-10 scale to them they can't assign a number to it. They say, "It hurts when I do this and when I do*

*that", but it is difficult for them to give a number to their pain."* (Physiotherapist, Jordan)

The scale also does not ascertain the type of pain, alongside the intensity, in order to understand the context. For example, a woman might experience agonising sharp pain on occasions, but an ongoing dull ache at all other times, thus in some appointments she might describe her pain as an 8, other times a 4. These qualitatively different types of pain may not be picked up by clinicians, unless they specifically probe, and the drop in intensity might (fallaciously) be considered positive.

*"The scale alone doesn't necessarily qualify their pain. They tell you how much pain they have but it doesn't tell you whether the type of pain is changing."* (Physiotherapist, Jordan)

Even when it is the main method of measurement used, clinicians can sometimes doubt the high score that patients give, not appreciating that if their patient lives with a high level of pain much of the time they have, out of necessity, found ways to cope or conceal.

*"I think it's used a stick by healthcare professionals, to say, 'They said their pain was 8/10 but then I saw them having a cigarette', it makes healthcare professionals think it's a nice solid construct, like you're an output, when it's not, and then when people do stuff, it's like, 'Well, you can't be in that much pain, can you!?', not really realising that you live with pain all the time" (expert in racial disparity, UK)*

The scale does not take into account that perceptions of pain differ across the menstrual cycle, with pain being

felt less acutely during ovulation and mid-cycle, versus pre-menstruation and during menstruation, which affects the number chosen by women. Thus, the numbers become arbitrary.

The scale is also a 'cold' and unempathetic way of measuring women's experiences. It was developed by men and tested on men. It does not take women's preferred ways of expressing pain into account and shuts down their qualitative expressions of pain.

*"A disadvantage is that it doesn't reflect the entire spectrum of pain and emotions that women feel... it's a bit cold, no emotion."* (Gynaecologist, China)

*"The 1 to 10 scale does not give them a way to describe their pain. It just gives them a way to indicate the intensity of it."* (Physiotherapist, Jordan)

*"When I think about the 1-10 scale, I think that it was just created by a man, for a man, and it made sense to them and it's not necessarily using the thought processes or language that women would have used if they were creating it."* (Positive-sex coach, writer, UK)

Although some women appreciate being able to convey the intensity of their pain using the scale, they would also like to explain their pain experiences in their own terms. They can perceive it to be of more use for clinicians than for them.

*"I think it was useful... more for them than for me, to be honest, I mean, just in terms of relaying the severity of something... At the time it would have been good to have been asked what*

*the experience is like when you're going through that heavy bleeding, 'Are there any other experiences you're going through?'. Just having some open questions would have allowed me to share...but none of that was really explored."* (Person with fibroids, UK)

Boiling pain down to a number diminishes the patient's experiences. The scale is essentially clinician-, rather than patient-, centred.

*"Especially in vaginismus and endometriosis, the people who talk about it, it isn't some casual pain, you know, the reactions are severe and when you're involved in that community and you're reading these stories from the women who are experiencing it on a regular basis, it's something that completely changes their lives and stops their lives, to ask them to rate their pain on a scale from 1-10, it would be rude to even ask, it's so foundationally disruptive."* (Sex-positive coach, writer, UK)

### **Implications for women with pain conditions**

Sole reliance on the 1-10 scale to understand women's pain reinforces the most negative aspects of the pain consultation: that it lacks empathy, and feels cold and clinical. It does not seek to understand women's pain in a way that is meaningful for them, but forces them to use a male-generated numerical system that does not acknowledge how pain is embedded in the lives of women.

While the 1-10 scale can have a place to help understand the intensity of pain that women experience, it is vital that it is used within a 'toolbox' that

allows women to express their pain in a way that is meaningful for them. The specialists we interviewed also use open questions and encourage their patients to use their own descriptors and language. Physiotherapists, in particular, also use emoticons and descriptors, plus photos of the body and genitals to allow women to point to areas that hurt, especially if they feel unable to say it or do not know the anatomical language.

*"Pictures work, and we have pictures of the genitals, where people can show you where things hurt, and body charts, for the pelvic pain, that all works."* (Senior Pelvic Health Physiotherapist, UK)

# 8. INDIVIDUAL PATIENT JOURNEYS



The women who took part in the research shared their pain stories with us, from the first time they felt pain and the journey they went on to find diagnosis and treatment. These journeys were often long and frustrating, leaving them in despair at times. These are just a selection of their experiences, in their own words:

**Sofia, has endometriosis, Argentina**

**Age she first experienced pain: 17 years old**

**Length of time to diagnosis and treatment: 18 years**

**Number of doctors seen: 5**

Sofia started her periods at the age of 13 years, and by the age of 17 she was experiencing intense pain during every period:

*The pain was my belly and ovaries hurt, you don't know how to describe it. Today I can say, after going through a pregnancy, that those were [like] labour contractions every 28 days. Very intense pains, disabling pains, because they were properly disabling.*

She didn't talk about it to anyone, and her mum told her pain was normal:

*I was 17 and couldn't talk about this with anybody. My mum would tell me, and I think every mum would say, "No, well, this is normal, it is normal." In fact, my mum suffered from this, but she had her first pregnancy at 22 years old.*

She consulted a gynaecologist, who gave her the contraceptive pill, assuming it to be severe period pain:

*At the time my doctor didn't raise the topic of endometriosis, she did not pose anything to be abnormal, she would say that with the hormone pills, those pains would calm down...she never talked that I could have a pathology. To her it was normal for me to feel pain when I got my period.*

The pain continued, and she was bedbound for at least two days a month:

*Years went by, although the pills reduced the pain a bit, the pain was still there. The first two days I was in bed. I would not get up from the bed.*

At the age of 30, she approached another doctor after as she was struggling to conceive. The doctor conducted several tests and told her everything was well:

*I bring it up, and the doctor tells me "Well, but it is too soon, generally people try for two years," and I tell her that I would like to start with tests. I go through several tests, basic routine ones. That test called hysterosalpingography, they inject you with a contrast liquid through the vagina, and in reality, what they do is see if the liquid circulates and that you don't have obstructions. This was all this doctor did to me. So, as everything is okay, and to her everything looks okay.*

Sofia was not convinced by this, so she went to see a fertility specialist. A friend had endometriosis and said her symptoms sounded similar, so she asked the doctor if endometriosis was a possibility, but was dismissed:

*At the fertility doctor, they did some tests, and they never talked about*

*endometriosis. At that point I brought it up, but they never talked about endometriosis. To them everything was normal... he does some other tests, he tells me that to him everything looks good, but that if I would like we could try a treatment, just like that. So I tell him that I would like to have a diagnosis, that I didn't want to try a fertility treatment just to try. I wanted to know what was going on with me.*

So, she went to see another doctor, who did fertility tests which suggested all was fine. Again, endometriosis was not considered, despite all the symptoms/signs being present: *So, I change doctors, she does some tests on me, all the tests results turn out okay, my husband's test results are okay. So up to that point the only conclusion was infertility, pain when/ during my period, pain during sexual intercourse. Which are all signs for endometriosis to any doctor that has knowledge about this disease. It is like these are the first basic items about this illness, and not that I don't have anything going on with me.*

Then she went to see a third (private) doctor, recommended by her friend who had an endometriosis diagnosis. By now she had been trying to conceive for five years. This doctor suspected endometriosis and arranged for a laparoscopy to confirm. This procedure confirmed Sofia had endometriosis:

*I went to the interview with this professional, I paid for the consultation because it wasn't covered by my insurance, it was a private doctor, but he was the one who diagnosed this person that had told me about this. We had a two-hour interview and the second time that I met with him was in*

*an operating room. This person did not doubt that I had that pathology. He did not doubt, he told me "I really will know when I open you up, but the reality is that the diagnosis of a 100% reliable endometriosis is with a laparoscopic surgery. There is no other way."*

The procedure confirmed that she endometriosis and treated it. Almost immediately she found relief from the pain she had suffered for 18 years:

*The first period I had after the surgery I noticed a huge difference with what my pains were since I was 17 years old. I went 18 years suffering from something that was solved with a laparoscopic surgery, that you enter in the morning and leave by the evening, and it's just three tiny holes. It is unbelievable.*

Sofia still struggled to conceive after this, so she had a second round of laparoscopy surgery for more spots of endometriosis. She still could not conceive, and went through several rounds of IVF, but sadly had a miscarriage. She finally managed to conceive and give birth to her daughter at the age of 40:

*As two years had gone by after the first surgery, I went through the second surgery, another cleanse was done, and then I started with the artificial inseminations with the IVF and after going through three IVFs, with freezing eggs in total I did six, I achieved my pregnancy. Overall, I went through 12 treatments. At first, I had a failed pregnancy that lasted seven weeks, I lost it, I had a natural abortion. Then, at my 40, after ten years of trying, I managed to become pregnant*

with [my daughter] who today is 4 years old.

**Alyona, has nodular adenomyosis, Russia**

**Age she first experienced pain: 16 years old**

**Length of time to diagnosis and treatment: 12 years**

**Number of doctors seen: 5+**

Alyona's pain started when she was a teenager. She visited her GP and was told nothing was wrong.

*I told my parents that I had some belly-aches periodically. And they said, "Well, go to the doctor. If it hurts, go."... I went, the doctor said, everything is fine with you. "Well, did you go?" "Yes, I did." They said, "OK." Well, if the doctor said normal, then normal.*

By the age of 18 (ten years ago), she was experiencing severe pain on a regular basis, but was given no diagnosis despite several hospital visits:

*In adolescence, in my early youth, at the age of eighteen or nineteen I regularly found myself in a hospital with some pain of unknown origin, where they made all sorts of checks and found nothing, after which they discharged me.*

She coped by taking pain killers, but began to rely on them daily:

*At night it hurt a little, I took something mechanically, and in the morning it seemed as if it hadn't happened. In the morning everything is perceived differently. And I did not notice at what*

*point it began to happen more and more, more and more often. That is, the intervals between these events became shorter, and at a certain moment I realised that I was in pain almost around the clock. That is, I was under medication all the time.*

She visited a gynaecologist but was misdiagnosed and kept returning to tell them she was still in pain:

*I went to a gynecologist in a private clinic...I was told, "You have some kind of neoplasm there." This was identified as myoma by ultrasound scan. At the same time, some of the U/S specialists said that it was a strange sort of myoma - with some liquid inclusion body. But this is unusual, there can be no liquid inside a muscular tumour. That is, they looked bewildered, but in addition to everything, myoma cannot hurt, I was also told about this several times. They, by and large, treated me friendly, but I did not receive any help from those visits. And I continued to go there and said: "Listen, well, it hurts!" Well, like, "I'm not crazy, well, it hurts. It's great that you say that in the place where it hurts, there is a benign formation that shouldn't hurt, but it hurts. What are we going to do about it?"*

Then the gynaecologist suggested she take some herbs and consider pregnancy as a solution:

*And then a gynecologist suggested for the first time, it seems to me, that I should take some medicinal herbs, Rhodiola algida and Orthilia secunda. I took thought and decided that I would not take anything and then they told me (I was nineteen or twenty years old then), they told me to start planning a pregnancy. Yes, planning a pregnancy*

*and enduring pain, because this is a woman's plight, it sounded like this.*

Alyona tried to put up with the pain, but it was impacting too much on her quality of life, so she visited another gynaecologist. She had read about using the contraceptive patch to help the pain, and bought it herself:

*"I bought a hormonal contraceptive patch, the lightest of those that I had. I think I told my parents that it was prescribed for me, but in fact I read something and decided that if I had at least some control of my cycle, it could improve the symptoms. That is, I sold this idea both to the doctor and relatives, I was the initiator, and I felt better. For a couple of months on hormones, it became calmer. Well, that is, more stable, but still there were shoots of pain."*

However, the pain started again, and was more severe, leading to her collapsing in 2013:

*One day I collapsed after an attack of pain right in front of my parents, because before that they knew about this [only] in my words, that I had a belly-ache, and then we were driving in the car for several days to visit my relatives, and they saw that I was crying, that I turned green and shaking, and I felt very bad. And I was all wet with cold sweat.*

Her parents helped her to find other doctors, but despite seeing several, she still had no diagnosis. She finally saw a surgeon who operated:

*I went to a gynecologist, I went to an MRI, I had radionuclide scanning of stomach and uterine tubes. I was given different diagnoses. Someone*

*continued to say that this was myoma, there was also an opinion that it is a rudimentary cancer of the uterus, and something else, I am not sure. Well, in general, there were several incompatible opinions and in the end I ended up with a surgeon in St. Petersburg, and she said, "No matter what is there, you feel very bad, this should be removed. And we will sort it out on the spot."*

After the operation, she was told she had a nodular form of adenomyosis/ endometriosis, and was given medication. However, the pain returned and she needed a second operation, but again the pain returned.

*And she removed it, and she was the first to tell me that it was endometriosis. She said that it was a chocolate-like mass in the wall of the uterus that they excised, that it was a nodular form of adenomyosis, which is collectively called endometriosis. They removed it and prescribed Jeanine [combined contraceptive pill] to me. For a while everything was normal, i.e. after the operation I felt normal, the things fell into place. But four months later the nodules came back while I was taking Jeanine. I had the second operation, [but] the pains also returned.*

So, she had a third operation to remove further nodes, and was given Vissane (progesterone therapy), which seemed to work well:

*I just feel like something has changed. I went for an ultrasound scan at a local outpatients' clinic, and they told me that, yes, I had some nodes there... and I went to the surgeon again, we talked with her and decided to remove it, and I started drinking Visanne, actually*

*Visanne is a medicine that gave me a helping hand over many years. I took it for a year, when on Visanne I felt fine, no new nodes appeared, I felt fine, and nothing hurt. A year later, I went off, and everything came back.*

However, there was still confusion regarding her diagnosis as the histology result still suggested fibroids:

*It is important to mention that according to histology, the first two tests, although the surgeons who cut me confirmed to me, according to histology, that I had a fibroid. The surgeons were left scratching their heads, because these were the drugs for endometriosis that helped me, and the surgeons saw with their eyes that it looked like a node of adenomyosis.*

However, it seemed there was an error at the hospital, as she asked another hospital to check her sample, and, finally, it was confirmed – in 2016 – that she actually had nodular adenomyosis:

*As I understand it, there was some kind of poor laboratory in this hospital, because when I got tired of it all and I took the specimens after the next operation to give them for analysis to another laboratory, the one that the surgeons also recommended to me, I immediately had the final conclusion, it was already in 2016, so I call it the year of diagnosis, I immediately received the answer that this was a node of adenomyosis.*

**Yanmin, has adenomyosis / endometriosis / dyspareunia, China**

**When she first experienced symptoms: 6 years old ago**

**Length of time to diagnosis and treatment: Various**

**Number of doctors seen: 3**

In 2014, Yanmin went to see a Chinese medicine doctor as she had heavy periods with blood clots. She was diagnosed with endometriosis and the treatment was successful:

*After some checks, he said that I had endometriosis and possibly uterine fibroids. Then I started to take Chinese medicine. After half a year, I got better and got pregnant again. I didn't plan to have a second child because I was old, and my health condition was not very good. The doctor also said that I don't need contraception because I certainly won't get pregnant. However, I still got pregnant by accident. The doctor said that I was a miracle.*

*I said, 'I didn't have this symptom before, why do I have endometriosis now? What to do, how to solve it, will it get better? The doctor said I had too many questions, don't worry, as long as I took medicine under her instructions, I will be well soon.*

Yanmin gave birth in 2016, and in 2017 she had discharge, heavy periods and dyspareunia. Her husband said she should go to see the doctor for help with the painful sex.

*My husband thought I was weird. I said it hurts. He said, 'How come it hurts?' I said, 'I don't know'. He said I should go to see a doctor...The doctor*

*enlightened me and said that I should be more open-minded and not reject my husband like this. He prescribed some lubricating oil. I applied some [lubricant] before intercourse, which makes me feel better... The doctor said I shouldn't think about that problem all the time, and I should relax. The doctor always tells me to relax, it's okay, and other people have pain too.*

She also went to see a gynaecologist for tests and was diagnosed with adenomyosis:

*"It was adenomyosis...she prescribed some medicine, including Chinese and Western medicine. I was very worried at the beginning because I have never heard of the disease before and, it is about the uterus...The doctor is very nice. She has been trying to comfort me, saying 'Don't be afraid, don't worry... You don't need to worry, because you have passed the child-bearing age and you don't have to give birth any more'... After seeing the doctor for almost a year, it has improved a lot."*

She found that the doctor did not give her much time in the consultation, nor answer her questions:

*She didn't have time to talk to me in detail... She only asked a few questions - how much was your menstrual flow, how many days was the menstrual period, and how painful it was. Then she touched my abdomen (just as the regular gynecological examination); she also pressed different parts and asked me whether it hurts here or there. After a few times, she said I can go on and pay for other examinations - vaginal B-ultrasound, a blood test, leucorrhea examination, and a urine test. Anyway, you have to pay for the*

*examinations first. It's almost impossible to talk to the doctor more because they are very busy.*

*I remember that I asked the doctor about when I can recover...she didn't answer and said why I had so many questions. All I need to is take the medication and follow her instruction. I understand her response because she is very busy; there are many people in the gynaecology department.*

When she experienced pain she could not speak to her husband, but confided in friends:

*I talked to my friend about these issues. I was in a dark mood, but I couldn't tell my husband. When I talked to my husband about this, he didn't understand, and he didn't know anything. He said that I should go to the doctor if I had any symptoms, and he is not the doctor. I just spared the efforts talking to him. Instead, I told my friends. When I talked to my friends, and I feel better.*

Her relationship with her husband suffered as a result of the conditions:

*Our relationship was very bad at that time. During that time, I was sick and not in the mood, and he didn't know how to comfort me. Anyway, it was a mess at the time...He had to take care of our children, so he is not in the mood to care about me. He also had to go grocery shopping and prepare dinner, so when I told him [that I'm in pain], he would only say, 'You don't need to tell me so much about it. You can see a doctor, and I am not a doctor, how can I know how to help you?' At that time, my husband had to do all the chores, so I felt sorry and didn't dare to annoy him with my negative*

feelings. All I can do is take good care of myself and get better as soon as possible

**Hala, has endometriosis / fibroids / adhesions, Saudi Arabia**

**Year she first experienced pain: Before 2005**

**Length of time to diagnosis and treatment: various**

**Number of doctors seen: 5+**

Before marriage, Hala suffered from 'inflammation and bad smelling discharge', but felt too embarrassed to tell anyone:

*I didn't tell my mum... because I once told my mum and she started shouting and was like, "This is because you lend your clothes to your friends and you don't listen to me! One of your friends could suffer from inflammations and she must've infected you! You don't listen to me!" so I didn't tell her anything anymore.*

She experienced pain when having sex with her husband for the first time (in 2005) and visited a doctor for help as her husband was angry:

*The night I was married I wasn't able to complete the sexual intercourse because of the severity of pain! I visited a doctor for this matter and she gave me an anaesthetic, I think the sexual intercourse actually took place after being married for 1 month, and when I completed the sexual intercourse I started suffering from the inflammation...I was very down and my mind was very busy and I was mentally tired and afraid, my husband was also mad.*

Hala then had difficulty conceiving - she had painful periods, and pain and bleeding during sex. She went to hospital for a hysterosalpingography in 2006 and was told she would not conceive due to adhesions, this eventually led to her divorce three years later:

*The doctor told me, "You will never be able to get pregnant because you suffer from adhesions! ... He spoke to me in a very rude and inappropriate way and I was so embarrassed so I started crying, when he saw me crying he gave me tissues and started talking properly to me and telling me that I will be able to have children through IVF... when my husband knew that I will have to go through an IVF he thought that this would be a hard thing so he gave up on me and got engaged to another woman! I then kept on suffering from bleeding until I got divorced. I stayed in my parents' house for years.*

She then had a hysteroscopy and was told she had uterine adhesions, fibroids and endometriosis. But she felt that this test was mainly for the benefit of showing student doctors how to carry it out, and she then had to repeat everything to another doctor in a different hospital: *I regret this experience, I wasn't benefited at all! It was only to show the students my case and the students kept on asking me questions and I answered them, the doctors didn't try to separate the adhesions in my tubes or cauterise the endometriosis!*

She continued to have follow-up appointments with a female doctor, for endometriosis and thickening of the endometrium. In this time, her

husband divorced her and she became engaged to another man:

*I got engaged and I wanted to marry because the doctor used to tell me that the AMH hormone is decreasing so I have to get married quickly and have children so I just wanted to get married so when a suitable man came to ask for my hand for marriage I got married immediately!*

She was also experiencing very heavy bleeding, with clots. Feeling that her current doctor was not treating her with respect, she went to see a different doctor in 2010, who advised that she had fibroids and needed an operation:

*When I used to go visit the [female] doctor I used to wait for her for hours and even not meet her sometimes and only meet her secretary. She was busy, performing a surgery, her secretary used to run the tests for me and then call the doctor to prescribe a medicine for me! I was so annoyed by this treatment, especially that her medical examination is very expensive! 400 riyals! Adding to that the fact that I wasn't getting any better, two years have passed by and I didn't notice any change which forces me to change the doctor.*

*I visited her [the new doctor] and we ran some tests and she told me that everything I'm suffering from is because of the tumour I have, she told me that I have to undergo a surgery and remove the tumour, this was exactly one month before my [second] marriage so my mother didn't accept to do the surgery before my marriage...I told my fiancé and he said that my mum was right and that we*

*should wait until after marriage and then do the surgery which I did.*

After her marriage she continued to have check-ups at the doctor, paid for by her husband's insurance. She used to go to the hospital for pain injections on occasions, including at A&E:

*My husband used to carry me like a young child and take me to the hospital so the pain can go.*

She was then transferred to a different hospital that had different equipment. Here she was told she needed an operation to remove the adhesions on her fallopian tubes. She was reluctant because she feared she would not be able to have IVF.

However, the IVF was successful, and she now has a son.

It was not possible to remove the endometriosis during the operation, however she had another operation one month ago which removed fibroids and some of the endometriosis. She is now experiencing early menopause and having treatment for a second IVF attempt. However, her ovaries have multiple cysts. She has also followed up with a psychiatrist due to the mental impact:

*When I'm 36 years old and I always hear that I will hit the menopause and stop getting my period while my sister is 52 years old and still gets her period it makes me so mad and sad! God bless her for sure but I start asking myself, "Why is this happening to me?" I honestly haven't told my husband about the menopause because this is my second marriage and when I was honest with my first husband he went*

and got engaged again so I won't be able to bear my current husband getting married as well, this way I would have to marry for the third time!

**Liz, has dyspareunia, UK**

**Length of time she has experienced pain: 15 years**

**Number of appointments with GP: 5**

**Successful treatments: 0**

Liz has had painful sex from her first sexual encounter at the age of 16 years:

*I was 16 and quite head-over-heels in love with my teenage boyfriend and we wanted to consummate our desire (!) and I think because it wasn't happening I was very worried that he was going to leave me, I thought, 'Well, if I can't give him the thing that all the other girls are able to give their boyfriends then he'll go find it somewhere else' and I think it really can break up relationships.*

She felt embarrassed and couldn't speak to anyone about it as she believed no one else had the problem:

*I definitely never spoke to friends about it because you have the idea that everyone else is having amazing sex and so, yeah, it felt like a bit of a bad secret and it was quite isolating... so it was something that I lived with very privately for a very, very long time.*

She finally mustered up the courage to speak to her GP after several months, but felt very 'dismissed', as if she was being frivolous:

*Initially, I felt very dismissed and very much told it was something I should*

*expect; I should expect for sex to be painful and that things would get easier...there's this feeling that you're taking up their time and that you're being indulgent and there's nothing actually wrong with you, and everyone else in the waiting room, they've got like broken legs and horrible diseases and all that's wrong with you is this one thing, so, yeah, just very dismissive, I think it was a slightly different quality of care than when I've gone in for other things.*

She went back several times to the GP over the ensuing years and found it be a distressing experience:

*I've probably been five times in total but the reason there around huge gaps between is because every time I've left feeling really unheard and not listened to and feeling, 'I won't do that again because not only was the experience in the room upsetting, but now I feel like I've been wasting their time'.*

She says that she used her own descriptors to explain the pain to the GP. However, she felt she would have benefitted from the doctor asking her to point out the areas of pain on a diagram:

*I think one certainly asked me to locate the pain. I would have always said, 'At the entrance of my vagina, like at the bottom of it, it's probably got a specific word, but just at the opening.' I think it would have been far more useful if they'd had a diagram or something for me to point to.*

Over the years she has been offered a sexual counselling (at the age of 16), transvaginal ultrasound, some anaesthetic cream, and ointment for Lichen Planus – but nothing has

helped her. It even left her questioning her own experience of pain at one point: *It's one of those things, I guess it's the same with mental health; if you can't see it, if it's not visible, then the treatment is so much more difficult, and I think the doctors really shut off, they're like, 'It's all in your head.'... they said those words, definitely, you just feel like you're taking them your experience and you leave feeling almost like, 'Well, maybe it isn't painful, maybe I'm not experiencing this?'*

She felt the doctor showed more concern when she said it was affecting her relationship – assuming it was impacting negatively on her male partner's satisfaction:

*They often became more worried if it was affecting your partner as well, I think that was a really big thing, which, again, felt sexist, it felt like they always assumed you were in a male/female partnership and they always worried about how it was affecting the man and how that then impacted on the relationship, not, 'Oh, it's affecting you, how does that impact the relationship?' I think I had one who offered couple's therapy to talk about it but it felt so much like it was about the other person.*

As she found little support or solution in the medical system, she has instead turned to educating herself and finding her own way through:

*With it has been a lot more to do with learning how my body works and feeling more comfortable with my body and being in relationships that feel safer because there is always that fear, I think it's very difficult to have this experience in a relationship that isn't supportive and I think a lot of*

*women end up having a lot of sex that they don't entirely want because they're worried that they aren't giving their partners enough.*

## 9. DIVERSE GROUPS



(NB Expert interviews conducted in Europe and Latin America region)

Issues of intersectionality – race, sexuality, gender identity and social class – affect the way women are treated within healthcare settings, and the diagnoses and treatment they are given. In turn, this impacts upon women's confidence regarding the medical system, and ultimately whether they seek help from the medical profession, or alternatively endure the pain, self-medicate or turn to alternative practitioners.

### Women of colour

Outdated ideas regarding women's pain conditions and race seem likely to influence both diagnoses and treatments offered to women of colour.<sup>58</sup> For example, endometriosis was historically deemed a 'disease of affluent, high-achieving women with private health insurance who have delayed marriage and childbearing'.<sup>59</sup> Buttram wrote in 1979: "Typically, our patients with endometriosis appear to have an intense desire to excel. They are usually well-dressed and have trim figures".<sup>60</sup> This suggested that women not seen in private medical care rarely had endometriosis, by which we might infer the supposed rarity among women from lower socioeconomic groupings, including women of colour. However, research in 1976 had already indicated the lack of difference between black and white women, and asserted that pelvic pain in black women was misdiagnosed.<sup>61</sup>

The Royal College of Obstetricians and Gynaecologist (RCOG) in the UK has shown that this misguided assumption of endometriosis as a 'white woman's disease', can lead to misdiagnosis and

delays in treatment for black women. Fibroids, in contrast, are known to be three times more prevalent in black women than in white women. As a result, some black women<sup>62</sup> are incorrectly diagnosed with fibroids, rather than endometriosis.

In terms of treatments, anecdotal evidence<sup>63</sup> suggests black women are more likely to be offered a hysterectomy to treat fibroids, versus white women.

*"A lot of black women will report fibroids... 'Have a hysterectomy', 'I don't want a hysterectomy', whereas if you speak to the very small number of other women who have fibroids, they've not been offered such a dramatic solution to their problem, they've been offered myomectomies or, you know, fancy things with drugs, MRIs and things like that, so I think it does need to be looked into."* (expert in racial disparity, UK)

Research indicates that black women's pain is more likely to be dismissed by doctors. In a Medical News Today interview<sup>64</sup>, black women from the UK told their stories of being discounted by doctors. For example, one woman, having suffered years of debilitating pain and vomiting due to the severity, and being continually dismissed by her doctor, finally queried whether she might have endometriosis or fibroids. Only then did the doctor consider it, and replied: 'Hmmm, maybe, as it's common in 'BAME' people'. However, the woman's pain was still not investigated, she was given the pill, and only much later discovered she had both severe endometriosis and fibroids.

Research by the All Party Parliamentary Group (UK) indicates that Black, Asian and mixed heritage women feel their pain is often psychologised by doctors<sup>65</sup>, for example written off as 'panic attacks'. In the same Medical News Today interview, one black woman was told by a male doctor, after a laparoscopy revealed no sign of endometriosis: "What you have done [supposedly wasting their time] is serious, and you need to consider if you have psychological problems." In fact, the patient already had a diagnosis of fibroids and had been encouraged to seek a laparoscopy by another female doctor.

Women of colour are subject to many stereotypes, for black women in particular this is around being 'strident' and 'difficult':

*"I think the label of a 'drama queen' or being 'bossy', etc. is applied much more readily to women of colour, absolutely, hands down."* (expert in racial disparity, UK)

*"I was noticing this pattern so much, we'd get called up and told, 'We have such a difficult woman, she's being ridiculous, she's really hard to nurse, she's been in before, terrible'... we did a reflective piece of work as part of the team... about that issue of this perception of the 'strong black woman' and the need to hold themselves up to expectations that are not articulated, nobody knows they're there, they're not surfaced, I think it's a trope and it's culturally embedded here in this country. I'd imagine it's embedded in a lot of places where there's been a colonial or a history of slavery."* (expert in racial disparity, UK)

The 'stereotype threat' leaves women feeling discounted, unable to speak about their pain, or at least cautious of sharing information. They turn away from mainstream medical care due to perceived mistreatment.<sup>66</sup>

In March 2020, the RCOG identified that: *'Black, Asian, and mixed heritage women are more likely to experience a lower quality of healthcare compared to white women. This often results in poorer health outcomes and reports of worse experiences with NHS services.'* They report continues to say that while socioeconomic factors had previously been considered the key reason for these disparities, increasingly research indicates that this is a simplistic interpretation. **In fact, ethnic disparities have been shown to exist regardless of socioeconomic grouping – that is, they affect Black, Asian and mixed heritage women from all groups.**

Alongside racial issues, there are also cultural issues which hinder clinicians' engagement with women presenting with gynaecological pain. Culture proscribes many aspects of the pain experience, such as pain expression, the type of remedies used, social roles and expectations, perceptions of the medical system, when/how/where to seek help, healthcare practices, illness beliefs and behaviours, and receptivity to medical care interventions.

The Endocul project<sup>67</sup> conducted research with women of African Caribbean, Chinese, Indian, Pakistani and Greek ethnic origin in the UK. They found that women from these minorities had experienced cultural insensitivity or misunderstandings in consultations – and often they were dismissed. Examples included having

to ask to be covered when having a bed bath (Muslim women) and doctors dismissing women who do not want to take the pill as they believe it is 'against nature' (Greek women). Cultural stereotyping is heightened when women do not speak English very well, for example, believing Asian women are subservient and not taking their concerns as seriously.

The study also showed that, while health professionals are committed to providing care for the individual, they do not understand, or incorporate, women's cultural values. For example, for South Asian women in particular, investigations and treatments can cause potential problems within their family and community: Virginity is thought to be potentially compromised by internal examinations (Muslim women); and oral contraception treatment can lead to suspicion of sexual activity (Indian and Pakistani women) - pre-marital sex is frowned upon.

In France, ethnic minority women - especially black women - face even greater bias, especially around the sexist myths of women exaggerating their pain and being 'hysterical', and the racist tropes of 'black skin being thicker':

*"When talking about pain management, the amount of painkillers you have to administer, or anaesthesia you have to administer to someone, and they consider black people, or immigrants, as exaggerating their pain."* (Semiotician, France)

*"Doctors and nurses think that black skin is tougher than Caucasian skin, so you have to go deeper, their pain is okay."* (Semiotician, France)

In Latin America, nineteenth century racist scientific discourse still heavily influences beliefs.

*"The medical profession in general has a bias, almost always because in the 19th century there was sort of like a scientific racism, where the racism that existed before begins to legitimise through the scientific discourse, which is seen as an objective discourse but in reality, it is not."* (expert in racial disparity, Latam)

*"The causes come because we all grew up in the same society, like we all heard granny saying, "You have to improve the race," and things like that, which are much more structural aspects...they point towards a scientific racism etc."* (expert in racial disparity, Latam)

Certain groups, especially indigenous people, within society are 'othered':

*"Idea of miscegenation, which is this national precept, there exists a very specific idea of what miscegenation is/ should be, I mean the mix between someone white and someone indigenous, almost always the white person had to be man, and the indigenous person a woman, and everything that is outside of that is pathologised, or relegated to the margins of society. And that is still a relevant configuration and organisation to what we see in Latin America. So the indigenous bodies, we do celebrate our indigenous past, but we do not want the indigenous people alive."* (expert in racial disparity, Latam)

This discourse and marginalisation, along with the symbolic power that clinicians hold, means that minority ethnic patients are in a powerless position. They are pushed towards

certain treatments regardless of their needs, and given no choice.

*"The consequences of a bias like this in a position of power as the medical profession, is that you think that it is in your hands to sterilise a person without their consent, because you know more than they do, and that is a big problem."* (expert in racial disparity, Latam)

Fear is prevalent among patients: Historical medical experimentation on bodies of people of colour and the economically disadvantaged has left many frightened to visit doctors.

*"There are a lot of women of a low social class, or Afro-descendant, or indigenous that because they know that they have been experimented with their bodies historically, their fathers or their grandmother or whatever, they are afraid to go to a doctor to say "I have this type of problem," because there is a history and they are scared... so, besides inequalities that come from the system to the person, the person in itself is afraid to access, and is afraid to go to certain doctors due to the history that their family, their ancestors have gone through, because they think they can be victims of something like that, right?"* (expert in racial disparity, Latam)

Those from rural areas, typically indigenous and poor, can be 'practice patients' for doctors in training, with errors rife.

*"The majority of doctors that are in the rural areas are young doctors. Doctors that are doing training there and afterwards... they go to the city. So, basically it is how the indigenous body is used as a guinea pig. That happens a*

*lot, there is a lot of malpractice because there is little supervision."* (expert in racial disparity, Latam)

Doctors have more respect for white women - they ask them (relatively more) questions and give them (relatively) greater choice of treatment. Social inequalities and the structural power relationship mean that women of colour do not have the tools or confidence to ask doctors questions or self-advocate. They are given no choice of treatment.

*"There's a thing that has come up in recent studies or academic works that is the confidence, in the fact that there are social inequalities and that the doctor is going to answer more the questions from the straight white woman, and the treatment is always going to be different, or that the same person, indigenous or black, doesn't have the tools to ask questions about this or that procedure, what is this or that problem, and well, the doctor, as they already have this stereotype bias they say "I know what's best for you, trust me. Take this, do that."* (expert in racial disparity, Latam)

Women of colour's lack of knowledge and resultant power within the medical system means they can be given the cheapest (and often less desirable or effective) treatments by doctors.

*"This also refers to more capitalist systems in which if there is a medicine that is cheaper and this person doesn't know that there is a medicine that is more expensive than the other one, well I'm going to give them the cheapest one, and generally worse, because I'm responding to a medical structural system here. It is cheaper for*

*me to put her the cheapest IUD.”*  
(expert in racial disparity, Latam)

They are routinely dismissed and experience disproportionate levels of malpractice. As a result, they lose faith in the medical system.

*“They lose faith in the medical community, that happens a lot. When there is really a problem or something like that, well, accessibility is a big issue because, let’s suppose, you start bleeding, you have thrombosis, or something like that, if you take long to arrive, I don’t know, like 3 to 5 hours, well there is a big possibility that the bleeding may be strong enough for you not to arrive on time to the clinic or hospital, whatever is the closest to you, and that is a big problem. Or, that there is a lot of malpractice, that you go to the doctor and they say: “Oh no, that is nothing.” Like, “Go away,” and when you get home well there the bleeding starts to be very strong, and when you try to go back well now you can’t”.*  
(expert in racial disparity, Latam)

### **Lesbians and Bisexual women**

The women in our research reported that doctors usually assume heterosexuality and it can be (even more) difficult to broach other types of sexual activity and associated pain. Experts echoed this.

*“Within the medical world, language is very binary and so it is very male/female, which is a shame and it makes it quite hard to talk about it in inclusive space, we’re in an arena where you’re talking about your genitals, to feel that it’s a communal experience, again,*

*because language is so important, to make it feel open and inclusive.”*  
(Person with dyspareunia, advocate, UK)

*“I’m 50 now, but we’re very much trained in heterosexual sex as being the thing and it’s actually surprisingly hard to get your head around anything else, even though my best friend is lesbian and I’ve got two friends who are transgender and have had gender reassignment surgery, so it’s not as if I’m not familiar with it from a personal context but somehow, when you get into the workplace, and because I see a lot of obstetric patients when I do my clinical work, they do tend to be more the male/female classic couple. So, yes, I think that’s something that does need challenging.”* (Senior Pelvic Health Physiotherapist UK)

Women in female-female relationships in the UK described doctors discussing the implications of their conditions on fertility, assuming that they were in male-female relationships. In France, they report lesbians being told that fertility issues are not relevant to them, and that they are ‘not having real sex’.

In Latam, there is more overt discrimination against lesbians and bisexual women. Non-heterosexuality is seen as a phase, it is not legitimate. This impacts upon the types of treatments offered.

*“If you have endometriosis, a lot of doctors refuse to give you contraceptive pills if you are from a different sexuality to the norm. That is the case with lesbian for example that it costs them a lot of work because they are for all of the effects, single women in a reproductive age. So, there are a lot of cases of lesbian*

*women that they coerce them into not taking contraceptive pills.”* (expert in racial disparity, Latam)

### **Other areas of diversity**

Other women we interviewed who had taken on informal advocacy roles shared their experiences and anecdotal evidence of other types of discrimination.

In France, in particular, disabled women, transgender men and women with larger bodies suffer discrimination when presenting with pain. Doctors make assumptions about the desire to have children, and women with larger bodies are lectured about their weight being a barrier to conceiving, despite not having raised the subject or wanting children.

*“For example, if someone is fat, they will get a lot of remarks from the doctor that have nothing to do with the specific issue, but will target their weight – as in, “You should really lose weight if you want to have children”. But maybe this woman does not want to have children. There are all these assumptions. So, these people avoid seeing gynaecologists.”* (Person with endometriosis, France)

People from these differing areas of diversity in France therefore fear seeing gynaecologists, and a ‘safe list’ has been created by women to enable them to have access.

*“For transgender people, or very fat people, or people with disability – [they] don’t have access. They definitely are discriminated, so now there is a website with a list of “safe” gynaecologists to see for those marginal populations, to avoid*

*being subjected to aggression and bad treatment.”* (Person with endometriosis, France)

### **Implications: intersectionality**

Intersectionality increases the difficulties women face when seeking medical help for their pain. Structures of power mean that women of colour and those who do not fit into the template of able-bodied or heterosexual normativity find themselves either having to hunt down ‘safe gynaecologists’, learn the cultural language of the medical profession in order to self-advocate, or – if they lack the confidence or means to do so – they may fall by the wayside and receive a lower standard of care for their needs.

# 10. IMPACT OF PAIN ON WOMEN'S LIVES



Pain conditions have significant impacts on many areas of women's lives, from work, to social life, to relationships and family.

The pain itself is often incapacitating, especially for conditions such as endometriosis and adenomyosis. Women we interviewed described needing to curl up in a ball, in agony, unable to do anything.

*"Often curled in a ball begging for it to end."* (Person with endometriosis, UK)

*"My husband used to ask me what are you feeling and I used to tell him that I'm dying and that I'm in pain while crying, he used to warm me up by heavy clothes and the heater."* (Person with endometriosis, Saudi Arabia)

For many women, the pain is so severe that it is a disability:

*"This pain affects directly, a person becomes to some extent disabled, I cannot say otherwise, because pain does not allow you to live a full life in general"* (Person with adenomyosis & endometriosis, Jordan)

*"I need to be in bed, in a foetal position, with ice and cannot go out, cannot do a physical activity, I do not feel like seeing anybody. For me that is a disabling pain."* (Person with endometriosis, Argentina)

On a day-to-day level, they have to carefully manage their pain, which means always ensuring they have a supply of painkillers with them. This in itself can create worries, as preparations such as codeine are addictive. In the absence of help from doctors this can lead to some women

researching other options and self-medicating.

*"All the time I have some package of painkillers at my fingertips, and at some point in time they stop working, and I start buying other pills, and if I don't have them, then I start to panic, I can start to get nervous, I can't concentrate on what I need to do if I suddenly realise that I left home forgetting my pills."* (Person with adenomyosis & endometriosis, Russia)

*"I decided to try self-therapy. I bought a hormonal contraceptive patch...I think I told my parents that it was prescribed for me, but in fact I read something and decided that if I had at least some control of my cycle, it could improve the symptoms."* (Person with adenomyosis & endometriosis, Russia)

The physical hangover from the pain is enduring, overwhelming fatigue and difficulty concentrating.

*"At the end it becomes a permanent fatigue... It cancels out everything, it saps any energy out of you."* (Person with endometriosis, France)

*"I have to rest, get sleep, that's the first thing, no matter what other urgent things I need to do, I have to put it aside, just to get the rest, that has a very big impact on me."* (Person with fibroids, UK)

### **Lack of fulfilment**

Pain limits women's lives. Everything has to be planned around it. Women struggle to take part in the everyday life activities one takes for granted - attending school, going to work, exercising, socialising. They feel that they have no control over their lives.

Plans can only be tentatively made and are often cancelled.

*"You stop attending events, stop going to school, stop going to physical activities. It is a strong impact, because when you feel the lack of understanding from the environment, what you have to say is "I am not feeling well," because what am I going to explain to a person? What should I do, minimise my pain? They are going to think, "She is not coming because she has her period." It deprives you from a lot of things and you do not express it due to the lack of comprehension on the other side."* (Person with endometriosis, Argentina)

*"You cannot normally focus on the movie you're watching. Your gaze narrows, you seem to fall out of it all the time in this pain. And when suddenly you have no pain for several days, you seem to be unable to breathe, trying to catch everything around you, and at the same time you are very scared, and you do all this under a monstrous fear that you absolutely do not control your life, you do not control your body and you don't know at what point you will be drawn in again. And you do not know how many hours, days without pain you have ahead. Now you have a day to do something and see your friends, and maybe two, or maybe in an hour it's all over."* (Person with adenomyosis & endometriosis, Russia)

Women feel cheated: they had dreams and aspirations that they feel they won't be able to fulfil. They feel that their lives have no semblance of normality - instead it revolves around their pain and lack of energy.

*"They feel that they've been cheated, like their life has been taken away, they have dreams and a lot of passions to fulfil and they just don't have the energy to be able to do those things."* (Person with fibroids, UK)

*"Crushed dreams."* (Person with endometriosis, UK)

*"Life is limited. Life is unfair, why me?"* (Person with endometriosis, Sweden)

### **Impact on school and work**

Women living with pain are sometimes unable to work or have to take regular days off. This leads to concerns that colleagues may feel resentful and that they may ultimately lose their jobs. Adolescents can struggle to attend school and miss vital lessons - one advocate with endometriosis told us she had even heard of doctors recommending girls leave school. The impact on concentration levels is also debilitating and contributes to daily work challenges.

*"It's also impacted things like work as well, whereas before I'd just be able to pop a few painkillers and just get on with life. In the last few months I wouldn't have been able to work, with the pain that I felt."* (Person with adenomyosis & endometriosis)

*"I couldn't focus on my work, I need a lot of brain power to do my work, so when I had this pain I couldn't think, so at the office I had to do simpler chores, nothing that required a lot of thinking, analysis, brain power."* (Person with ovarian cyst, Malaysia)

*"When you can even get together with friends or sit somewhere in a lecture hall at the university, but at the same*

*time you seem to be in a fog and not in focus. I just remember I could sit swaying from side to side to remain conscious, in human consciousness, but you cannot get involved in what is happening outside, because you are sucked back inside, like into a black hole.”* (Person with adenomyosis & endometriosis, Russia)

### **Psychological impact**

*“Psychologically it is even harder than physically.”* (Person with endometriosis, France)

Multiple factors of living with chronic pain conditions create psychological distress. Enduring the pain itself can leave women feeling helpless and despairing. The impact on life and dreams can lead to depression.

*“You get depressed, you cry, get anguished. It disables you even more than the disablement that you already have due to the pain.”* (Person with endometriosis, Argentina)

Living with these pain conditions can be a lonely experience. Women feel that others often do not understand their pain and minimise it. The continual battle with doctors for diagnosis and treatment grinds them down. This can lead to them self-censoring – they do not speak about their pain, but try to endure.

*“It’s the normalisation, people just don’t believe you, they think it’s all in your head, that it’s a psychological problem.”* (Person with endometriosis, Sweden)

*“Nobody knows what I have been through. The woman is really patient and she bears all kinds of pain...I feel*

*bad about myself because nobody cares or nobody is sympathising with me.”* (Person with adenomyosis, Jordan)

*“One does not speak, and in reality, what should be done is the complete opposite. Express it, speak about it.”* (Person with endometriosis, Russia)

For some women, the impact can be severe, leading to utter despair and thoughts of taking their own lives. Experts say that this is a serious and under-acknowledged outcome that needs urgent attention.

*“Feel heart-pounded together, desperate, rushing to the sky, complaining to the sky and the earth, feeling that I don’t want to live anymore, I want to die, and I feel very heavy/down, I ask God why torturing me, I don’t know why this is happening, I don’t know what to do; I feel so weak that I am about to die; how can there be such pain in the world?”* (Person with adenomyosis, China)

*“Yes, there are many cases of depression. This is not discussed enough but there are certainly links to suicide impulses, and some who have committed it.”* (Endometriosis Specialist, France)

### **Impact on body image**

Women who suffered from abdominal bloating as a symptom of their pain condition also reported feeling less confident in terms of body image. They described the bloating as being very visible, to the point that they had to buy larger sized, or maternity, clothes. This led many to feel anxious or self-conscious about going out into

public, where others sometimes made unsolicited comments about their appearance, such as asking if they were pregnant, or gave them weight loss advice. They felt unattractive as a result.

*“When people say, ‘Ooh, when’s your baby due?’ and I say, ‘Oh, no, I’ve got this thing, it’s called endometriosis’ and then they say, ‘Oh, what’s that?’...it just makes you feel disgusting as well, when I look at my body I just feel, like, disgusting.”* (Person with adenomyosis & endometriosis, UK)

### **Impact on relationships**

The impact of women’s pain conditions on relationships is significant.

For conditions such as endometriosis especially, some women feel that their partner does not understand the intense or ongoing nature of the pain and may have little sympathy. They may minimise or dismiss their pain, not wanting to hear about. A few women we interviewed gave anecdotal evidence of other women they knew, whose partners became angry or violent, leading to the women being careful to hide their pain so as not to ‘provoke’ him.

*“Wanting my husband to comfort me or saying something kind. But instead, he has a strong temper and would yell at me and no empathy for my pain at all, just ask me to see the doctor.”* (Person with adenomyosis, China)

*“The husband is...too busy and tired. The wife is very careful with words and action, trying not to provoke him.”* (Person with adenomyosis, China)

Women feel a high level of guilt. They believe they disappoint their partners when unable to socialise or do activities together. In heterosexual households that subscribe to a traditional gender division of work, women can struggle to carry out childcare and the housework. They often feel guilty, and their partners may also resent taking over what they perceive to be women’s work, even believing her to just be lazy.

*“[They say] We can’t go out when he wants – I have to disappoint him.”* (Gynaecologist, Sweden)

*“There is guilt because the husband takes over all the family responsibilities from cooking and baby caring with her lying in the bed doing nothing.”* (Person with adenomyosis & endometriosis, Russia)

### **Impact of pain on women’s lives: painful sex**

Alongside the physical pain experienced, societal pressure – in particular to provide sexual satisfaction for others – can lead to secondary pain: the emotional pain that women experience as a result of dyspareunia and the profound impact this can have on their self-esteem and relationships.

### **Impact on self-esteem**

For those who have it as a primary condition, painful sex can make them question themselves as sexual beings. They wonder if there is something wrong with them, that they may be unable to feel pleasure, or whether they might be asexual. This can easily turn into a vicious circle of anxiety, where they approach each encounter with trepidation, unsure whether they

can trust their bodies. When their body doesn't work in the perceived 'normal' way, they feel like failures.

*"There's an anxiety about whether you are wet enough and feeling like a failure."* (Person with dyspareunia, UK)

### Impact on self-trust

Again, for those with dyspareunia as a primary condition, if they do not find a cause (and thus solution) for the condition it can leave them questioning their experiences and wondering whether it is real. This is exacerbated if doctors say or imply it is 'all in their head'. This leads to women blaming themselves and feeling ashamed.

*"Patients go years talking to general doctors, and not getting a diagnosis, getting studies that don't point to anything. Vulvodynia, for example, is not seen in a study. In a neuropathy, you can't always see it, very specific tests and doctors do. Patients say what they feel and are misunderstood. They need to be listened to and understood."* (Physiotherapist, Argentina)

### Impact on relationships

A feeling of guilt is hugely prevalent for women with dyspareunia due to any cause. They worry about disappointing and letting down partners.

*"I try to escape from it and he does the same. It is a problem and I feel bad inside. What is the solution? What shall I do? I want a solution to solve this issue for us."* (Person with Endometriosis, Saudi Arabia)

When communication about sex is difficult between partners, women may be unaware that their partner may be happy not to have penetrative sex, and would be happy to find pleasure in other ways that would not cause her pain. Thus, she may spend many years feeling guilty and 'a failure'.

*"Thinking that their partner expects just one certain thing and that they're not able to deliver that, or they want to deliver that even if it hurts them, it's so, so common... women thinking that their partner wanted one thing from them, been with them for 10 years and doing that one thing over and over again and finally that partner was actually like, 'I don't want this, what's been happening this whole time!'"* (Sex-positive coach, writer, UK)

Some women, who have either found no solution or who find it too embarrassing to seek help, see no choice but to avoid sex completely, thus missing out on pleasure and connection with their partners.

*"In terms of the impact of pain on women's lives, a big one actually is avoidance; feeling like you don't have a solution, you don't think that it's possible to solve it, so you just avoid it completely and take away that source of pleasure and self-expression from your life. One woman said, 'I just didn't have sex and I didn't really miss it because it was never fun for me anyway' and all of her self-fulfilment of sex was from fantasy because she just didn't even think it was possible to enjoy sex with other people, so she didn't want it. Really, only 1% of the world's population is asexual, so most people are sexual beings and want to have sex and sexual fulfilment but when so many people experience pain,*

*one really, really common result is that they avoid it, which is just such a shame, if you think that they could be feeling so much joy."* (Sex-positive coach, writer, UK)

Some women worry that their partner will leave the relationship to find sexual satisfaction elsewhere, which increases the pressure and anxiety they experience.

*"There's this idea that men have this insatiable sexual appetite and if they're not fed regularly they'll go elsewhere."* (Person with dyspareunia, UK)

*"Women have been taught, 'You have to please your men, and he can switch you for another one if he is not happy with you, and he won't stay with you if you don't respond the way he wants you to respond'."* (Sexologist, Colombia)

*"Women are afraid that their partners will leave them."* (Person with Endometriosis, Sweden)

*"For Muslims, yes, it would definitely impact their relationships because in their culture they have polygamy, so men can marry more than one woman, so they feel very threatened and vulnerable when they can't perform for their husband - in my University Hospital days I saw more of that; they didn't feel stable in their relationships."* (Physiotherapist, Malaysia)

While some women do have an understanding partner, others find that their partner is not so understanding and has affairs or leaves the relationship.

*"Women, well, they refuse having sex. As a result, they lose their husbands;*

*unfortunately he goes to his mistress or... Well, usually he abandons the family."* (Person with Endometriosis, France)

Those not currently in relationships experience anxiety that they will never be able to have a long-term relationship, as they believe men will reject them once they know about their condition. This has a detrimental effect on their self-confidence, leading to depression and despair for some. Some may hesitate to date new people to avoid the perceived shame.

*"There's also mental problems associated with it; 'Will I ever meet a man that can live with me and my pains, because I'm not very easy to live with?'"* (Person with Endometriosis, Sweden)

*"I hesitate to date men because it's already possible to feel my myoma. When I lay, the myoma feels like a hillock. A big hillock! And how can I have sex? I'm ashamed to have sex with a man. It's the end of my life. I can't imagine my life without men, I would rather die. I see no future, only darkness... My life is ending. Only darkness and despair."* (Person with dyspareunia, Russia)

Some women feel utterly hopeless and decide to give up seeking a partner altogether - they feel 'faulty' and abnormal, and beyond help. They decide it is safer to be single and celibate, than risk the rejection, shame and ensuing sadness.

*"Around avoidance and it's that giving up, thinking that they're different, that they're not the same as they're seen in culture and assuming that there isn't a solution for them, or perhaps they've*

*tried solutions themselves but they haven't found any success from them and that there's so much shame involved in pursuing a better solution and they don't believe it will work anyway, so why go through the bother?"* (Sex-positive coach, writer, UK)

### **Impact of pain on lives: Implications**

Women's pain has a far-reaching impact on their lives. The lack of compassion that women often experience, and the resultant shame they feel is embedded within the taboos regarding women's pain conditions. There is a lack of education, and hence understanding, regarding women's pain. Sexism means that female employees with pain conditions still do not receive equal treatment, and may be driven out of the workforce. Young women, encouraged to drop out of school, are seemingly dispensable.

Understanding can lead to empathy. Although work is starting to be done to bring women's pain into the spotlight (in some countries), our research indicates there is still some way to go. Women's pain conditions, including painful sex, need to be perceptually brought under the umbrella of other pain conditions that are afforded respect and compassion. Healthcare providers, schools, the media and brands all have a role to play in educating, challenging perceptions, and enabling women's voices to be heard and respected. Training is needed for employers so they understand the validity of women's pain conditions and ensure that fair policies are created and adhered to.

# 11. THE ROLE OF GOOD LANGUAGE IN PAIN



## The importance of empathy in consultations

While all of the women we interviewed had had at least one (usually more) negative healthcare experience, most eventually experienced a consultation that felt more positive.

Crucially, positive experiences involved clinicians conveying empathy. Women consistently described doctors that seemed to understand that the consultation might be anxiety-provoking and embarrassing, and behaved with consideration. They did not rush their patient, but allowed her story to unfold as she saw fit and at her pace, while they listened with intent. They asked open questions when needed – which some women had never experienced before. Tonally, they conveyed a relaxed and open manner. They offered reassurance and women felt at ease. They also acted as guardians of their patient's confidentiality, ensuring patients attending with relatives could speak to them alone if preferred.

*"The doctor is very nice. She has been trying to comfort me, saying, 'Don't be afraid, don't worry. You don't need to worry.'"* (Person with adenomyosis, China)

*"She didn't appear rushed, even though I had the same amount of time, her body language didn't appear rushed."* (Person with fibroids, UK)

*"So, when I went to the endometriosis specialist consultation...he started inquiring: 'When you have sexual intercourse, does it hurt?' 'Your period?' I mean, the other doctors, neither the fertility doctor, nor the*

*gynaecologists...never inquired about what I felt or suffered every 28 days."* (Person with endometriosis, Argentina)

*"If the mother is with her. I would tell the mother, 'Please wait outside. I have an issue and I would like to talk to your daughter and you do not have the right to know it'. So, from that point of view, my patients used to come and say the most secret issue and they are free to say that. There is a bond between me and my patients especially the young ones."* (Gynaecologist, Saudi Arabia)

*"Gynecologists are a little like psychologists. If we do not listen to the woman, and if we don't understand her, she is not coming back."* (Gynaecologist, Colombia)

Empathy was also conveyed through being open and speaking to the patient on their level. This involved using jargon-free language, explaining in a clear, but non-patronising manner, and answering questions with respect. Treatment choices were given, and the treatment plan decided together, taking into account the women's preferences and concerns. The care was patient-centred – the women felt that they were respected throughout as actors with capacity to explain their pain and understand clinician's explanations and implications, and agency to make decisions about their treatment options.

*"Now I like the doctor, because she explains to me everything that happens and the risks in a balanced and understandable way...There is a feeling that we are a team, and we solve some problems together.... We spoke openly, but the final decision is*

*to be taken by me."* (Person with adenomyosis & endometriosis, Russia)

Freedom of expression was also implicit to a positive consultation. Women felt 'heard' when allowed to describe their experiences and pain using their own words, rather than being solely directed by the clinician.

*"She listened a lot more attentively and asked me more about how I was feeling, why I'd come back for a second consultation, so I did share my distress."* (Person with fibroids, UK)

Our research suggests that women feel more respected when asked to describe their pain, and when 'heard' empathically. However, a history of not being asked, and a lack of confidence, can mean some women may find it challenging. There is, therefore, a need for tools to enable them to unlock and express it.

## Communication of pain: the role of metaphors

As highlighted earlier, the communication of pain is difficult – both for the speaker to express, and for the listener to understand.

Metaphors play an important role in personal narratives, as they 'enable the reflection and communication of complex topics' (Moser, 2000<sup>68</sup>). They are not just figures of speech, but are the way humans structure their thoughts: "We actually understand the world with metaphors and do not just speak with them" (Kövecses, 2005).<sup>69</sup>


Metaphors have long been understood as tools people use to express pain. Physician David Biro (2011), who writes about the

'expressibility' of pain, suggests that there is no literal language for pain and it can only be described through metaphor: "Pain is an all-consuming internal experience that threatens to destroy everything except itself and can only be described metaphorically."<sup>70</sup> Shinebourne & Smith (2010) suggest patients' metaphors are a 'safe bridge' which allows them to express emotions they find too difficult to communicate literally.<sup>71</sup>

A key barrier in the consultation process can be women feeling that the clinician does not empathise or understand their pain. The field of narrative medicine suggests that clinicians actually become more empathic towards their patient when they engage with the patient's narrative, including metaphors. Jack Coulehan (2003) writes:

*"Medicine is largely about storytelling and interpretation, and narrative, metaphor and symbol are fundamental tools of the trade...patients understand their narratives in a narrative way whether physicians understand it or not. If this is so, and if physicians ignore or devalue narrative, then health care is bound to suffer."*<sup>72</sup>

The McGill Pain Questionnaire goes some way towards enabling patients to express their pain through metaphor. It was developed to help patients describe their pain and comprises a list of 78 descriptive adjectives, including metaphors, grouped together that patients can choose – e.g. 'flickering/beating', 'jumping/shooting', 'pricking/lancinating', 'sharp/lacerating'. The adjectives and metaphors were gathered from both medical literature and patients. Deborah Padfield (2013)<sup>73</sup>



comments on the potential limitations of this, saying these are “patients from a distinct community with a distinct vocabulary not necessarily reflecting the language the majority of patients might actually use, e.g. ‘lacerating’ and ‘lancinating’.” The questionnaire may therefore reflect the language of certain types of patients, for example, white, middle class who were more likely to vocalise their pain in appointments. (Despite being a well-known questionnaire, none of the participants in our research mentioned it.)

Other research suggests there is a communication gap between health professionals and patients regarding metaphors and pain experiences. Skelton, Wearn & Hobbs (2002) analysed the differences between metaphors used by general practitioners and patients to describe symptoms in the UK. They show that doctors tend to use ‘body as a machine’ metaphors (e.g. ‘wear and tear’), whereas patients prefer more evocative metaphoric expressions.<sup>74</sup> Clinicians also view the language they use as having universal meaning, but patients may not understand it in the same way. Kirmayer (1992) writes: “‘Blood’ for the patient is not ‘blood’ for the physician. The inability to see the metaphoric and contextual basis of discourse limits the physician’s comprehension of the patient’s life-world”.<sup>75</sup>

**This highlights the vital importance of clinicians understanding patient-generated metaphors – from myriad groups – learning the language of their lived-experience.**

# 12. WOMEN'S PAIN METAPHORS AND DESCRIPTORS



The women living with pain conditions that we interviewed shared with us the language they use to describe their pain. Clinicians working directly with women also shared the descriptors they commonly hear in practice.

There were a large number of universal pain metaphors – that is, descriptors we heard across cultures. Some linguists believe these arise from universal bodily experiences<sup>76</sup>.

However, metaphors for pain are not immutable, they change over time and are affected by cultural paradigms e.g. medical philosophy, science, religion, symbols and myths. For example, in Western culture, the twentieth century saw the emergence of pain metaphors revolving around germs and military warfare.

We identified a number of themes of metaphors used by women in different countries:

In China, pain metaphors often reflect the concepts of traditional Chinese medical philosophy regarding imbalance and harmony. 'Warmth' versus 'coldness' and 'blockages' emerge frequently. TCM concepts include: maintaining Yin and Yang, by balancing 'warmth' versus 'coolness' within the body; keeping the Five Elements - the heart (fire), kidney (water), liver (wood), spleen (earth), and lung (metal) - in harmony; and Chi [Qi] which moves the energy of the vital substance of life throughout the whole body. Chi blockages are thought to lead to illness.

*"In the West they might say, 'My arm feels uncomfortable' but in Chinese we'll tell you, 'I feel hot', 'I feel cold' and use the specific area of the body,*

*[instead of] 'My arm feels uncomfortable' or, 'My skin feels uncomfortable', so one would say, 'Cold in the arm', it is of course physical, you feel the body temperature, but sometimes it's a feeling; you feel that you are cold."* (Semiotician, China)

*"The underlying belief in Chinese medicine is that you feel pain because this part of your body is blocked – for example, if you have muscle pain it feels like stone, it's very hard, because you've put too much tension on it, so you need to loosen it up, or your stomach feels pain because you've inhaled too much cold air that day, so your cold and heat doesn't balance."* (Semiotician, China)

The 'heart' is sometimes used in metaphors. In China, the heart is considered to co-ordinate holistic bodily functions, as well as directing other organs to ensure the balance of physiological functions.

Generally, Chinese metaphors tend to be less 'expressive', as this can be seen as an exaggeration or manipulation to seek attention.

*"If you use a more emotional or a more colourful way to describe the pain, others would feel you were exaggerating a little bit and feel that you're using it to ask a lot from others because pain is related with not being loved, so you are pressing others to show that they care about you."* (Semiotician, China)

In Russia, agricultural and machinery metaphors were more prevalent (linked to soviet themes around workers and technological utopianism). Generally, the Russian metaphors we heard were also more evocative.

In Sweden, metaphors regarding blood in the context animals were more prevalent versus other European countries.

When thinking about descriptive language, it is also important to remember that individual characteristics and personality impact upon expression. Some of the women we interviewed were involved in the creative fields, and felt more at ease speaking in evocative language.

**The following are the metaphors and descriptive language that women shared with us per condition, grouped into themes where possible:**

#### **Endometriosis:**

(NB pain levels and experiences varied between women)

#### **Stabbing:**

- *Like scissors stabbing my tubes.* (Person with endometriosis, adenomyosis & fibroids, Argentina)
- *I used to feel like someone is stabbing me with a knife.* (Person with endometriosis, Jordan)
- *It's like knives cutting.* (Person with endometriosis, Saudi Arabia)
- *Stabbing with a jagged knife* (Person with endometriosis, Russia)
- *It feels like a hot, searing knife stabbing you.* (Gynaecologist, Russia)
- *It's like knitting needles stabbing me.* (Physiotherapist, Russia)
- *Constant stabbing in the stomach.* (Gynaecologist, Russia)
- *Knife in the back.* (Gynaecologist, Russia)

- *Intense stabbing in my side.* (Gynaecologist, Russia)
- *It's like a knife in the back, dagger pain.* (Neurologist, Russia)
- *Feel as if someone is hitting you with knives.* (Gynaecologist, Russia)
- *Having Ninjas with swords cutting them inside.* (Gynaecologist, Russia)
- *Cutting pain and it's typical before the period.* (Gynaecologist, Russia)
- *Like having a knife and then a big hammer is taken and smashes it deep.* (Person with endometriosis, Sweden)
- *It feels like a knife turning around in my organs.* (Person with endometriosis, Sweden)
- *Pain associated with ovulation is like knife stabbing.* (Person with endometriosis, Sweden)
- *Stabbing pain in crotch.* (Person with endometriosis, UK)
- *Stabbing pain in the ovaries like being stabbed by a knife that can radiate up to the buttock and to the vagina.* (Person with endometriosis, France)
- *Like someone cut my meat with a sharp knife.* (Person with adenomyosis & endometriosis, China)
- *The pain is like being cut, and my heart is strangled when it hurts.* (Person with adenomyosis & endometriosis, China)

#### **Cutting:**

#### **Pins / needles**

- *I knit, and I knitted a uterus with the ovaries and I filled it with pins, with hooks...that is how I feel sometimes, right? It is as if I am nailed all over.* (Person with

endometriosis, adenomyosis & fibroids, Argentina)

- *It's like pins and needles in my lower parts.* (Person with endometriosis, Russia)
- *In my thighs it is like needles... this feeling of sharp pain.* (Person with endometriosis, Russia)
- *It feels like I have a thousand needles in there.* (Person with endometriosis, Jordan)
- *Thousands of pins and needles stabbing me.* (Person with endometriosis, UK)
- *Feel like a human Voodoo doll* (Person with endometriosis, UK)
- *A sharp pain from time to time as if someone planted pins in my lower back.* (Person with endometriosis, France)
- *I feel like needles are placed into the sides of my thighs with strings threaded through them, and someone pulls on the strings. It really hurts a lot.* (Person with endometriosis, France)
- *Like pins and needles* (Gynaecologist, Sweden)

#### **Barbed wire in uterus**

- *Uterine contractions are like a barbed wire hoop that presses and squeezes my entire uterus, the pain is constant without respite, it is exhausting.* (Person with endometriosis, UK)

#### **Crushed glass**

- *It feels like I have ground glass everywhere and when I move, it moves around and just cuts me inside.* (Person with endometriosis, Sweden)

#### **Violence metaphors: smashing, battering, punched, pulled, ripped**

- *Hammer smashing in the pelvis* (Person with endometriosis, Russia)
- *Bashed in the sides with Thor's hammer.* (Person with endometriosis, Russia)
- *Sometimes pain is like a rubber hammer which beats me.* (Person with endometriosis, Russia)
- *Domestic abuser inside me smashing my insides apart* (Person with endometriosis, Russia)
- *Body is being ripped apart* (Gynaecologist, Russia)
- *Pulled apart with a jack hammer* (Gynaecologist, Russia)
- *They feel their ovaries are impaled.* (Gynaecologist, Russia)
- *Ball and chain smashing into the pelvis.* (Person with endometriosis, UK)
- *It's breaking me from the inside* (Person with endometriosis, UK)
- *Battered with a large sledgehammer.* (Person with endometriosis, UK)
- *Punched in the stomach by heavyweight champion of the world.* (Person with endometriosis, UK)
- *During menstruation in the lower back it is as if I had received millions of punches and had millions of bruises.* (Person with endometriosis, France)
- *They tell me that it's like somebody's 'punched' them, somebody's 'kicked' them in the lower abdomen and it's cyclic, so it's like receiving multiple kicks or punches* (Gynaecologist, Malaysia)
- *Ripping me out from the inside* (Physiotherapist, Jordan)

- *Two cats fighting/scratching inside my belly.* (Person with endometriosis, adenomyosis & fibroids, Argentina)

#### **Construction machinery (Russia)**

- *This pain reminds of a drill rotating in different modes. It feels like it drills down my abdomen and the lower back* (Person with endometriosis, Russia)
- *It feels like I have a mixer in there which cuts me.* (Person with endometriosis & ovarian cyst, Russia)

#### **Heat:**

#### **Poker, lava, fireball, burning, on fire**

- *It feels like a fireball in the right side, I can even feel the intestines. I have a burning pain, it burns in the right side, and it's very close to the abdomen* (Person with endometriosis, Russia)
- *It feels like this fireball would blow out, I want to physically remove it from my belly. It feels like a fire inside my belly* (Person with endometriosis, Russia)
- *Hot, poker type shooting pains in your lady bits; your vagina and your bottom.* (Person with adenomyosis & endometriosis, Russia)
- *In my stomach - lava- like a volcano eruption.* (Person with endometriosis & ovarian cyst, Russia)

#### **Burning**

- *The lower back is like a little pit of fire, where it can increase or decrease, depending on how everything's going.* (Person with endometriosis & ovarian cyst, UK)
- *Burning, smouldering, blistering, all that language around 'heat', and sometimes that feeling of heat, or burning almost makes you cold as well, it's a strange kind of feeling.* (Person with endometriosis & ovarian cyst UK)
- *It feels like my hips are on fire.* (Person with endometriosis & ovarian cyst, UK)
- *It feels like my womb is on fire* (Person with endometriosis & ovarian cyst, UK)
- *It feels like I'm being burned* (Person with endometriosis & ovarian cyst UK)
- *It's so intense, it's making me shiver.* (Person with endometriosis & ovarian cyst UK)
- *Like a bonfire, when it's so bad, that bonfire spreads all around the hips, the lower back, the tops of the legs.* (Person with endometriosis & ovarian cyst, UK)

#### **Delivery pain / contractions:**

- *It is exactly like delivery labour* (Person with endometriosis, Saudi Arabia)
- *It is very tiring. The woman cannot withstand the delivery labour for 2-3 hours, we stand these pains for months* (Person with endometriosis, Saudi Arabia)
- *I feel that I am giving birth and my labour takes a long time* (Person with endometriosis, Saudi Arabia)

- *I feel that the baby is stuck inside.* (Person with endometriosis, Saudi Arabia)
- *It's labour contractions every 28 days.* (Person with endometriosis, Argentina)
- *I suffered from harsh contractions, it's like something being ripped inside me.* (Person with endometriosis, Argentina)
- *Contraction type pain, so that's like somebody squeezing and then letting go repeatedly* (Person with endometriosis & adenomyosis, UK)

#### **Radiation of pain:**

- *It radiates to my thighs, so that I can't feel them.* (Person with endometriosis, Russia)
- *Irradiating pain because the pain impacts on other organs.* (Person with endometriosis, Russia)
- *Radiates up your back and down your legs.* (Person with endometriosis, Russia)
- *Starts in vagina and radiates up through my chest.* (Person with endometriosis, Sweden)
- *Radiating from your lower back and hips, you're just in the foetal position, it's just unbearable* (Person with endometriosis & ovarian cyst, UK)

#### **Can include radioactivity, in Russia**

- *Like a Chernobyl that has exploded inside me.* (Person with endometriosis, Russia)

#### **Aching/dull:**

- *Constant aching.* (Person with endometriosis, Russia)
- *It's the same pain as having the flu.* (Gynaecologist, Russia)

- *A kind of aching but it is a dull pain, as aching dull pain* (Physiotherapist, Jordan)
- *Aching legs, aching bones* (Person with endometriosis, UK)
- *Cutting pain is not as common as dull pain.* (Person with endometriosis, UK)

#### **Other sensations:**

##### **Pressure**

- *My pain was the feeling of having a finger in the vagina pressing very hard on the upper wall of the uterus (and therefore on my bladder) all the time.* (Person with endometriosis, France)
- *The pain is in the right side which goes to the lower back and to the anal orifice, you know, and it presses down, presses down. It feels like I have dumbbells inside* (Person with endometriosis & ovarian cyst, Russia)
- *If we talk about images, I see everything in a black light. It feels like I'm small and chained up, and there is something which presses me down.* (Person with endometriosis & ovarian cyst, Russia)
- *There's also rectal pain and sometimes the women describe it as a pressing inside the stomach.* (Gynaecologist, Sweden)

##### **Bursting**

- *My uterus will burst* (Physiotherapist, Russia)

#### **Twisting**

- *It's twisting inside me, twisting my uterus.* (Physiotherapist, Russia)

#### **Throbbing**

- *It's a throbbing pain, it comes and goes and the throbbing becomes worse and worse, until I can't bear it.* (Person with endometriosis, UK)
- *It starts from my lower back, then it goes to the belly, to the right side... It's like a toothache, it's also tuning and shooting pain but very, very intense.* (Person with endometriosis & ovarian cyst, Russia)

#### **Twitch (China)**

- *'It feels like a twitch', that's commonly said.* (Gynaecologist, China)

#### **Swelling**

- *Something swelling inside, inside the abdomen.* (Gynaecologist, Sweden)

#### **Stretching**

- *My whole uterus is stretching* (Person with endometriosis, France)

#### **Numbness**

- *There's numbness in the thighs* (Person with endometriosis, Saudi Arabia)

#### **Heaviness**

- *They say it's like being really constipated, when you're straining you feel a heaviness* (Senior Pelvic Health Physiotherapist, UK)

#### **Shooting pain**

- *It's like it starts in my stomach and it goes down, it shoots down into my lady region.* (Person with endometriosis & adenomyosis, UK)

#### **Split in half**

- *I felt like my back is detaching and that I'm divided into two* (Person with endometriosis, Saudi Arabia)

#### **Tightness**

- *Like someone has placed a corset on you and tightened it so tight can't breathe.* (Person with endometriosis, UK)
- *Tightness in the stomach.* (Person with endometriosis, Russia)

#### **Electric shocks in body (France)**

- *Did we talk about the back ... its needles again... actually almost like electric charges/ shocks* (Person with endometriosis, France)
- *Like lightning.* (Person with endometriosis, France)
- *I feel like electric charges – it's as if someone grabs my nerves, pinches them and plays with them.* (Person with endometriosis, France)

### Electric shocks in head (France)

- Sparks in my head and arms – I have horrible headaches. (Person with endometriosis, France)

### Dull vibration: brass Instruments (France)

- I imagine brass instruments – that will make a very low and dull sound. During the contraction it is impossible to breathe – it cuts the respiration, and then there is the feeling like a brass instrument that reverberates through the belly and beyond. (Person with endometriosis, France)

### Pain in the ovaries: grabbing, ripping, twisting, broken glass, burning, pinching, squeezing

- Grabs my ovaries and rips them. (Person with endometriosis, Argentina)
- In the ovaries, it is like needles They are like “tiki, tiki, tiki,” like you are getting pinched, and pinched, and pinched, and pinched. (Person with endometriosis, adenomyosis & fibroids, Argentina)
- As if someone would come and would squeeze your ovary, and would enlarge it, and they squeeze it and enlarge it. (Person with endometriosis, adenomyosis & fibroids, Argentina)
- This feels like if someone took your ovaries, turned them around and pulled on them. (Person with endometriosis, UK)
- In my ovaries – it feels like broken glass. (Person with endometriosis, France)

### Headaches

- Ice-pick headaches (Physiotherapist, Russia)
- Headaches of hell (Physiotherapist, Russia)
- It's ringing in my ears (Physiotherapist, Russia)
- There's darkness in my eyes (Physiotherapist, Russia)
- Head's splitting. (Physiotherapist, Russia)

### Want to curl up in a ball

- Contractions, the shooting pains, the stabbing, sharp pains, where you just want to curl up in a ball and die. (Person with adenomyosis & endometriosis, UK)
- They say they want to curl up in a ball. (Gynaecologist, Russia)

### Fibroids:

#### Metaphors of the body (UK)

- A car with rusty spark plugs, you know, you've got the car but the spark plugs are rusty, so, therefore, the car's not performing, (Person with fibroids, UK)
- The week before a period I felt like I was full of toxins, I felt like I was just about to burst like totally pent up; pent up emotions, pent up toxins that are kind of trapped in your body really, that's the best way to describe it. (Person with fibroids, UK)

### Heaviness

- Sometimes difficulty emptying the bowels, or IBS, or it can cause or aggravate the feeling of

prolapse, so they'll describe a heaviness, a dragging, an ache in the stomach. (Person with fibroids, UK)

- Heaviness in my abdomen. (Gynaecologist, Jordan)

### Pressure

- I have pressure at the lower pelvis. (Gynaecologist, Jordan)

### Twisting

- Twisting kind of experience because when I turned, the cord, or the stalk, twisted and the pain was excruciating, so it was like a twisting kind of a cord. (Person with fibroids, UK)
- Like an umbilical cord being twisted and when I made a jerky movement it was very, very uncomfortable. (Person with fibroids, UK)

### Stabbing pain

- Stabbing pains, a lot sharper, almost like a knife pain. (Person with fibroids, UK)
- It feels like a dagger which hits a number of organs... An iron dagger, it's severe and this dagger turns inside you... Just imagine any horror film... You know how the maniacs are portrayed, how they mock the victim... It's the emotions of pain (Person with fibroids, Jordan)

### Hammers banging

- Hammers just below the belly button area, right across, from left to right, lots of hammers

banging and the same with the lower back. (Person with fibroids, UK)

### Squeezing

- Squeezing... This word attracts me the most... iron vice clamps It's like the tortures in the Middle Ages. (Person with fibroids, Russia)

### Buckled over

- Buckled over, crippled over (Person with fibroids, UK)

### Stretching

- There is something stretching in my abdomen. (Person with fibroids, Jordan)

### Adenomyosis

NB: Respondents often had adenomyosis and endometriosis, so they were not always able to distinguish the individual pain.

### Stabbing/Cutting

- As if something with sharp tools entered my body tearing and hurting me. (Gynaecologist, Jordan)

### Wound-like

- Like wound soaked in salt water or alcohol. (Person with adenomyosis & endometriosis, China)
- It is like a wound. I feel that it is like the wound. (Person with adenomyosis, Jordan)

### Heavy / dull / dragging

- It feels very dull, heavy, and ballooned with the period stuck inside. (Person with adenomyosis & endometriosis, China)
- The pain on this side is more like a dragging pain, that's the adenomyosis, it's more like a dragging pain. (Person with endometriosis & adenomyosis UK)

### Ripples / Radiation passing through

- From the belly running down the right leg, like a wave rolling down there. (Person with adenomyosis & endometriosis, Russia)
- Yes, just the pain passing. Like the radioactivity, you have the pain here; then you have the pain in other parts, even the back. (Person with adenomyosis & endometriosis, China)
- Sciatic pain, I get cramp in my leg and then it kind of goes on the hip, down my leg, so that can wake me up in the night, it's like a dull continuous ache that just kind of goes down my leg, so I wouldn't say it's a shooting pain, it just gradually moves down my thigh, to my knee. (Person with endometriosis & adenomyosis, UK)

### Needles

- It's like an injection, and it hurts (Person with adenomyosis, Jordan)
- Pain in perineum, like a needle sticking in me. (Person with adenomyosis, Jordan)

### Delivery pain

- The pain in my stomach is like beginning of delivery labour (Person with adenomyosis & endometriosis, China)

### Balloon on fire (UK)

- You know when you blow up a bubble gum balloon and it's getting thinner and thinner and thinner? Instead of it getting thinner, there's just more flames (Person with endometriosis & adenomyosis, UK)
- Balloon that was on fire, that's just getting bigger and bigger and bigger. (Person with endometriosis & adenomyosis, UK)

### Ants moving on the body (Jordan)

- My legs have pain and shaking as if ants are moving on my body, on my legs, arms and back, i.e. all over my body. (Person with adenomyosis, Jordan)

### Stretched

- As if something is being stretched inside you. (Person with adenomyosis & endometriosis, Russia)

### Squeezed

- Uterus is being squeezed out like a doormat. (Person with adenomyosis & endometriosis, Russia)

### Feels like parts of the body are broken

- It feels like my lumbar spine was broken. (Person with adenomyosis & endometriosis, China)
- The waist feels broken. (Person with adenomyosis & endometriosis, China)

### Sticking

- Feel like my muscles were sticking together in my thighs (Person with adenomyosis & endometriosis, China)

### Twisted

- The belly is like intestines twisted together; and at the same time (Person with adenomyosis & endometriosis, China)
- It feels like something is tangled together and twisted together (Person with adenomyosis & endometriosis, China)

### Caught in a clamp

- Like meat caught by a clamp, like being pinched. (Person with adenomyosis, Jordan)

### Being strangled

- Like being strangled and hard to breathe. (Person with adenomyosis & endometriosis, China)

### Electricity

- It is like holding electrical wires and hitting something electricity in back and abdomen. (Person with adenomyosis, Jordan)

- My everyday pain is like electricity and thunderstorm (Person with adenomyosis, Jordan)
- Small pinches...like when you touch something that gives you an electric shock. (Person with endometriosis, adenomyosis & fibroids, Argentina)

### Post Sex:

### Sore pain after orgasm

- When you orgasm you kind of tense up, don't you?... it's really sore and tender the next day and then hurts a lot more. You don't get the shooting pains or the contractions, it's just like a really sore kind of pain. (Person with adenomyosis, UK)

### Like a muscle burn

- Very sore, like when you work out and you get muscle burn a day or so after, it's a bit like that. (Person with adenomyosis, UK)

### Ovarian Cysts

### Pressing pain

- I had a very terrible period pain and the pain was going on and off, on and off and during the on time the pain was getting worse, it felt like a 'pressing' in my abdomen, below my belly button. (Person with ovarian cyst, Malaysia)
- Pressing pain, like a dumbbell (Person with ovarian cyst, Malaysia)

## Pulling pain

- *It was pulling on the left side, the pain was so intense, the pulling started from behind my hip and then it pulled to the inside of my womb. (Person with ovarian cyst, Malaysia)*
- *It felt like a rope, like someone was pulling the rope, it's 'like a tug-of-war. (Person with ovarian cyst, Jordan)*
- *For the pulling pain I'd draw a rope and put it between the hip and the belly button, I'd have the rope dangling on the left hip, that describes the pulling pain, it sometimes comes from behind my hip. (Person with ovarian cyst, Jordan)*

## Sex with nails

- *When you have sex, you get cramp-like pain in your belly as if you were hit in the belly with something sharp, like nails (Person with ovarian cyst, Russia)*

## Headaches

- *Steam coming out of my head, that's how it feels, my head feels very hot, very warm, that's the image that comes to mind (Person with ovarian cyst, Malaysia)*

## Swollen Abdomen – endometriosis, adenomyosis, fibroids, ovarian cysts

### Bloating

- *It's a dull bloating kind of pain (Gynaecologist, Sweden)*
- *I was bloating, the amount of people that were asking me when my baby was due and I*

*was like, 'I'm not pregnant, my body just hates me!' (Person with adenomyosis & endometriosis, UK)*

- *Bloating...heaviness, like a heavy bloating. (Person with adenomyosis & endometriosis, UK)*
- *I feel bloated. You know when you see pregnant women rubbing their bellies? Well, that's what I have to do to ease it a little bit, so it is like an inflamed kind of swelling. (Person with endometriosis & adenomyosis, UK)*

### Internal gas

- *It's like a fart going the wrong way. (Gynaecologist, Sweden)*
- *It's like it's trying to get out of the bowel wall instead of going down and that can be very, very painful. (Gynaecologist, Russia)*
- *Constant popping sensation in uterus. (Gynaecologist, Russia)*
- *Irradiating pain, because the pain impacts on other organs (Gynaecologist - expert in endometriosis, Russia)*

### Look pregnant

- *Like I'm 6-8 months preggers (Person with endometriosis, UK)*

### Object, person, animal inside

- *Like a balloon growing inside (Person with endometriosis, Russia)*
- *Something swells inside me, it's like a balloon inside (Physiotherapist, Russia)*
- *Uterus like heavy watermelon (Person with endometriosis, UK)*

- *Buddha in belly. (Person with endometriosis, UK)*
- *Large stone in the stomach (Person with endometriosis, UK)*
- *Feels like you're carrying this bowling ball around in your stomach. (Person with adenomyosis & endometriosis, UK)*

### Look like an animal

- *Horrid beached whale. (Person with endometriosis, UK)*
- *It's a gazelle to a hippo in 24/7 (Person with adenomyosis & endometriosis, UK)*

### Heavy Bleeding (especially endometriosis and fibroids)

### Water flows

- *It's just a flood. (Gynaecologist, Sweden)*
- *It's like waterfall. (Gynaecologist, Sweden)*
- *Raining cats and dogs (Gynaecologist, Russia)*
- *The rain comes pouring down (Person with Fibroids, UK)*
- *It's gushing out of me. (Gynaecologist, Sweden)*
- *It's pouring out of me. (Gynaecologist, Sweden)*
- *Flood of blood. (Gynaecologist, Sweden)*
- *Bathed in blood. (Person with Endometriosis, France)*

### Animals – Sweden

- *Oh, I bleed like a pig! (Gynaecologist, Sweden)*
- *Bleed like a stabbed pig. (Gynaecologist, Sweden)*

### Drained:

- *Nearly bled out. (Gynaecologist, Sweden)*
- *It's draining me. (Gynaecologist, Sweden)*
- *Lifeless. (Person with Fibroids, UK)*

### Painful Sex

#### Descriptions for endometriosis, adenomyosis, fibroids and ovarian cysts

Most of the women we spoke to with these conditions experienced painful sex due to their conditions, and used the descriptors below. As conditions are often comorbid, women can be unsure which causes the pain.

Sometimes women with these conditions have painful sex due to the conditions, but it can then become a vicious circle, whereby they dread sex, fail to become aroused and/or their muscles clench, and they can then develop a secondary painful sex condition such as vaginismus or dyspareunia (which we will explore next).

### Partner feels too big

- *Every time he pushes inside of me it feels like he's too big. (Gynaecologist, Sweden)*
- *He's too long. (Gynaecologist, Sweden)*
- *It feels like it comes too far in. (Gynaecologist, Sweden)*

### Friction/burning

- *Like every time you grate, it's like [grating noise]. (Gynaecologist, Sweden)*

- *It feels like a cheese grater inside of me.* (Person with endometriosis, UK)
- *Vagina rubbing against wood* (Person with endometriosis, Saudi Arabia)
- *They feel a burning, there's unpleasant friction.* (Neurologist, Russia)

### Soreness

- *It doesn't matter which position we're in, there's always the sore spot.* (Gynaecologist, Sweden)
- *It feels like it hits a sore spot inside of me that he keeps on hitting* (Gynaecologist Sweden)

### Object inside

- *Someone's hitting me with a hammer.* (Person with endometriosis, UK)
- *Penetration hurts, it feels deep. It feels like a javelin coming into you.* (Person with Endometriosis, Sweden)

### Birth cramps

- *There are other women who say it's more like a dull ache, like a weight, and they say it feels like stomach cramps, or like giving birth, contractions.* (Sex-positive coach, writer, UK)

### Pushing

- *It pushes on my back.* (Person with Endometriosis, Sweden)

### Stretching

- *It feels like he's stretching my tissues, so that it hurts* (Gynaecologist, Sweden)

### Sharpness

- *It's quite a sharp pain, it's not a continuous pain, it's a sharp pain* (Gynaecologist, Sweden)

### Stone

- *They say their stomach feels like a 'stone' and when they're next to their partner they feel a stiffness inside their belly and it feels like 'stone'.* (Physiotherapist, Malaysia)

### Balloons inside body

- *Bubbles and balloons in my lower abdomen. If I insert my finger inside them they burst and cause a very severe pain like delivery labour with any movement* (Person with adenomyosis, Jordan)

### Turbulence inside

- *I feel like there's a tornado inside me or an earthquake.* (Person with endometriosis, Saudi Arabia)

### Like a bruise

- *I don't know if you have ever hit yourself with something on some muscle and it left a big bruise, and when somebody goes touch that bruise you feel like a pain that spreads everywhere.* (Person with endometriosis, adenomyosis & Fibroids, Argentina)

## Descriptions for painful sex conditions:

### Dyspareunia

#### Burning ball

- *It does feel just like a burning ball pain, glowing...it glows like a hot ember.* (Person with dyspareunia, UK)

#### Pushing down

- *Pushing down feeling, a pressing, pressure.* (Person with dyspareunia, UK)

#### Brick wall

- *Brick wall, feeling that there was a wall.* (Person with dyspareunia, UK)

#### Speed bump

- *There is a rough patch...almost 'like a little speed bump.* (Person with dyspareunia, UK)

#### Blockage

- *Like a blockage, like a dead end* (Person with dyspareunia, UK)

#### Like moon landing

- *Initiating penetration is 'Like a moon landing' – for example, films in space, where the two ships have to dock, I feel like I'm seeing Apollo 13 in my head, and even if it's a centimetre out, 'This is not going to work'.* (Person with dyspareunia, UK)

## Vaginismus

### Wall

- *Like a wall, nothing could go in.* (Gynaecologist, Sweden)

### Heat

- *Upon touch it feels like a sharp burning sensation.* (Gynaecologist, Sweden)
- *Hot inside me.* (Gynaecologist, Sweden)
- *It's more like cinders, I think, it's not like a raging fire, it's more like you have these cinders, where every time you move it's like a burning.* (Gynaecologist, Sweden)
- *Like somebody takes a cinder log or something and just holds it against you.* (Gynaecologist, Sweden)
- *It's like burning irons* (Gynaecologist, Sweden)
- *Like a burning iron, it makes them shy back.* (Gynaecologist, Sweden)

### Knives

- *Ring of knives.* (Gynaecologist, Sweden)

### Multiple sensations

- *The pain is described as something that opens up and it's going to break, in this case, the entrance to your vagina. Excessive tension, burning, stabbing.* (Physiotherapist, Argentina)

## Vulvodynia

### Sharpness

- *It's a pang, a sharp pain, some say it's a deep, dull pang and some say it's like a sharp, burning, stabbing pain, they describe it as a very sudden, strong, instant pain, rather than a gradual onset* (Physiotherapist, Malaysia)
- *It's like sticking a sharp finger nail into your skin.* (Physiotherapist, Malaysia)

### Cutting

- *Sometimes they describe it as a knife going in and cutting* (Physiotherapist, Malaysia)

### Friction

- *Like friction, that something's stuck and it feels abrasive, that's how they describe vulvodynia* (Physiotherapist, Malaysia)

### Stabbing and radiating

- *For vulvodynia it is more like stabbing pain kind of starting in one area and spreading out* (Senior Pelvic Health Physiotherapist, UK)

### Burning

- *It's a burning sensation* (Physiotherapist, Argentina)
- *Fire in the area.* (Physiotherapist, Argentina)

### Impact on Life

Some women used very descriptive metaphors to describe the impact of pain conditions on their lives:

## 'Darkness' to convey despair

- *My whole world is dark. Like a sky covered by black cloud without any light or hope.* (Person with adenomyosis, Jordan)

### Like a dark force in your life

- *You cannot live a normal life, it is as if something is falling on everything around you, some dark force, the power of darkness.* (Person with adenomyosis & endometriosis, Russia)

### Black Lotus

- *The topic of illness, pain, there is also a beautiful image, "Foam of Days" by Boris Vian, a book where the main character dies from the fact that a flower blooms in her lungs, in my opinion, a lotus, and at some point I had an idea to tattoo a lotus on my belly in the place where I constantly had nodes, a lotus flower that blooms there endless.. What colour would this flower be? Black, a black lotus.* (Person with adenomyosis & endometriosis, Russia)

### Black hole

- *A black hole, that pain pulls you somewhere, that the world fades at this moment and loses its lustre...you cease to belong to yourself, that it's very scary, that this is all before and after, and during, despair, helplessness, well, loneliness.* (Person with adenomyosis & endometriosis, Russia)

## Dark Sky

- *I used to live a fuller life: love, family, joy, sex... Now I feel like I'm an under-woman, I'm miserable and I'm desperate. For example, currently I'm lying on bed and writhing in pain, I'm taking spasmolytics. I'm living on these pills. The sky is always dark, and I'm always in depression.* (Person with endometriosis, Russia)

### Vampire

- *Like a vampire has sucked every bit of life blood from them.* (Gynaecologist, Sweden)

### In gaol

- *I get tired very quickly. I feel like I'm in gaol. There is no personal life: only me and my uterine myoma.* (Person with fibroids, Russia)

### Imprisoned in body

- *They actually feel imprisoned in their own bodies.* (Person with endometriosis, France)

# 13. PAIN DICTIONARY

Libresse

Against this background of women's stories, research indicates there is space for an enhanced tool to reinforce the legitimacy of women's pain and help them to vocalise it. The importance of metaphors in allowing women to express their pain, and helping clinicians to empathise, suggests they are key to the 'lexicon'. The dictionary would enable both women and clinicians to 'speak the same language', in a way that is meaningful for women. It could be used both before, and during, the consultation.

*"Yes, so they can choose words and descriptions, yeah, that would be helpful because often if you ask someone to describe the pain, their mind goes blank and they just don't know."* (Person with ovarian cyst, Malaysia)

*"It would help a lot of people because they'll say, 'I have pain', people don't think about words to describe their pain, like the questions you've been asking me, they don't think in that way, you just think, 'I have pain', pain is pain and it's difficult to explain."* (Person with endometriosis, Sweden)

*"It sounds good because, some people cannot use very descriptive words but use a lot of like opinion words, 'It feels bad' - well, that's not really describing what it is, so I think it would be good in that respect because I think some doctors hear that and think, 'Oh, it's bad for you but it might not be bad for somebody else', you know, it's subjective, 'Oh, it feels rubbish', 'Oh, well, life's rubbish', kind of thing. So it would be good to have specific words to describe the pain properly so that everyone's on the same page, that*

*would be very important."* (Person with endometriosis, UK)

*"It would help a lot of people because they'll say, 'I have pain', people don't think about words to describe their pain, like the questions you've been asking me, they don't think in that way, you just think, 'I have pain', pain is pain and it's difficult to explain."* (Gynaecologist, Russia)

*"There definitely needs to be less medical jargon and more pain descriptors that they [patients] usually use, like I said, 'pressing' pain, 'punching' pain, 'kicking' pain, things like that - in the medical profession we should use layman's language."* (GP specialising in women's pain conditions, Malaysia)

It is important that the dictionary is multilingual and comprises metaphors from across cultures, to ensure an inclusive conversation.

*"I think it's a brilliant idea to start you on the blocks of going for an assessment or going to get help and particularly for women who might feel undermined or might not have the confidence or even the language, you know, women whose English is not their first language, that sort of thing. So, I think having a pain dictionary and having a translation of that into different languages would be a fantastic idea."* (Physiotherapist, Jordan)

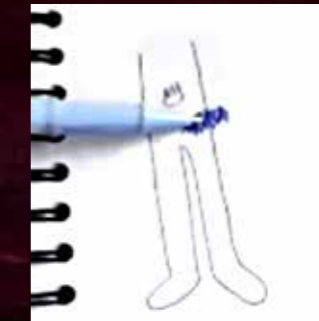
However, people have different way of processing, and best expressing, information. While language is one such way, other routes - include imagery - bring to life pain in ways that some women may find difficult to vocalise. This is borne out by research

conducted by the artist Deborah Padfield<sup>77</sup> into visual representations of women's pain, which she turned into 'pain cards' for use within patient/clinician consultations. The pain dictionary should therefore also include pictorial depictions of evocative metaphors and women's expression of pain, thus allowing women the space to express pain in the 'language' most meaningful to them.

*"I work a lot with images. I believe that the more visual the explanation is the woman understands better and she identifies more with these images... I believe that definitely in this dictionary... it would have to be a lot of visuals, so that the woman identifies herself... the pain from atrophy in sexual relations is like the fire that they could feel at the level of the vagina or during sexual intercourse, that they feel like something burning."* (Gynaecologist, Colombia)

As highlighted earlier, research indicates that a 'toolkit' is important in consultations when understanding women's pain. The pain dictionary could provide a qualitative, visceral understanding, used alongside the 1-10 scale to track the quantitative experience of pain over the trajectory of the condition. It is also clear that some women either do not know the names of their anatomy, or feel embarrassed to say the word. Our research also suggests that drawings of the reproductive system and genitals also be used, for women to point out. Within research interviews with women, we used a projective psycho-drawing technique, which is helps people access and express feelings they may not be able to reach

with words. This technique enabled some women to provide a rich depiction of their pain experiences. We suggest that this could also be used within the 'pain narrative' toolkit.



*"Here is where my ovary is and it's just kind of like this scribbling, just mess, it's like 'white noise', and that's where all of the burning lies."* (Person with endometriosis, UK)



*"There's the wall and that's sometimes a problem, not always. There's a hot spot there, which looks like a little flame but it's actually meant to be a vulva, but a flame is very poetic, so I'll go with that! Sometimes it feels like it's on fire.... So there's the wall, which is the hot spot, it smarts like a little blast, like an 'Ooph!' It's a flame in the sense that if I felt something hot I'd take my hand away, it's a twang' just like, 'Ooph!' but then also associated with that is a feeling of dryness, a vagina desert."* (Person with dyspareunia, UK)

# 14. CONCLUSIONS AND IMPLICATIONS



Our research adds to the mounting evidence that women who have painful gynaecological conditions often feel dismissed and discounted across society. In our qualitative interviews, we heard harrowing stories from women that centred around a lack of equality and empathy: within their personal relationships where they often felt they had to minimise their pain; in the workplace where they tried to push through pain for fear of losing their jobs; and in medical consultations where they did not feel heard in terms of either their pain or their preferred treatments. We heard the far-reaching ways in which pain conditions affected women's lives, aside from the horror of enduring ongoing pain: the secondary pain of lost relationships; depression and despair; unfulfilled dreams and ambitions.

Women's pain is embedded within intertwined cultural beliefs regarding sex, shame and women's roles. The taboo of speaking frankly about sex organs and sex means women are often silenced. The historic prioritisation of men's sexual satisfaction means some women are unaware that pain during sex is not normal or that they too have a right to experience sexual pleasure. Alongside this, women are seen to be 'hysterical' and to catastrophise their pain, while at the same time their pain is normalised and almost fetishised as the woman's 'lot' to stoically endure. As a result, women are often reticent to seek help and when they do, these issues are often played out within the medical consultation.

The women who participated in our research often had long journeys to diagnosis and saw several clinicians

before finally finding an answer. They described multiple experiences where clinicians had little empathy, discounted their questions and concerns, and pushed them towards certain treatments (while often omitting to mention others). They reported that doctors often reinforced society's perceptions that female pain should be endured, and in some instances their pain was overtly psychologised and they were sent to see psychiatrists. For women with dyspareunia, some doctors mainly concerned themselves with the impact on the male partner's sexual satisfaction and even suggested the pain was 'just in their heads'.

Women left medical consultations feeling belittled and not believed, even questioning whether they were genuinely in pain. After seeing several doctors and receiving no diagnosis, but contradictory information, some felt the only way forward was to self-advocate. They joined support groups and organisations, read up on women's pain conditions and returned to doctors armed with this information. Some were lucky and visited empathetic doctors that other women had recommended, who worked with them to find a suitable treatment. Others discovered that some doctors do not like women who question them.

Some women, however, do not have the self-confidence or lack access to information to self-advocate. These are typically those with the least amount of cultural power: women of colour, women from lower socioeconomic groupings, the disabled and LGBTQIA+. Our research joins previous studies in identifying that these women are

often stigmatised within medical consultations.

Despite the medical field shifting generally towards more patient-centred care, a marked doctor/patient power imbalance seems evident within some consultations regarding women's pain. Women feel they are often not asked to describe their pain or the impact it has on their lives. In contrast, for those who experienced positive consultations, clinician empathy was a key feature of good outcome: understanding that the appointment might be anxiety-provoking and embarrassing, allowing the patient to tell her story at her pace, listening with intent, using jargon-free language and collaborating on treatment plans. The care was patient-centred, with women feeling respected as having capacity to explain their pain.

However, a history of not being asked, and a lack of confidence, can mean some women may find it challenging to express their pain. There is, therefore, a need for more tools to enable them to unlock and express it.


Communication of pain is notoriously difficult and a choice of 'tools' is required to enable women to express it. Research indicates that sole use of the 1-10 pain measurement scale serves to close down women's pain experience, reducing it to a number on a scale. It is a subjective measurement and does not acknowledge that not everyone is able to conceptualise pain as a number. In contrast, the use of metaphors - seen by pain specialists as the 'language of pain' - can engender empathy in the listener, and as such could foster a better understanding between patient and clinician. The

McGill Pain Questionnaire goes part of the way with this, using pain adjectives and metaphors for patients to select, but it does not represent language used across all sections of society.

The women we interviewed provided many metaphors that expressed their pain vividly. We therefore propose that there is space for a new pain dictionary comprising these metaphors, enabling both women and clinicians to 'speak the same language'. It is important that the dictionary is multilingual and comprises metaphors from across cultures, to ensure an inclusive conversation.

Moreover, as people have different ways of processing and communicating information, we suggest the dictionary could be more powerfully expressive by including pictorial depictions of evocative metaphors and women's descriptors of pain.

The experts and women that we interviewed believed that a pain dictionary would enable women to discuss their pain in a more meaningful way. We propose that it be used within a 'pain narrative' toolkit, with the pain dictionary providing a qualitative, visceral understanding, used alongside the 1-10 scale to track the quantitative experience of pain over the trajectory of the condition. We also suggest using tools such as the projective psycho-drawing technique within the 'pain narrative' toolkit, as another way to enable women to access feelings they may not be able to reach with words, as well as diagrams of the reproductive system and genitals, to allow women to point out part of the body they either cannot, or are too shy to, name.



As a final note, although women's pain is slowly being brought into the spotlight (in some countries), our research suggests there is still some way to go. Women's pain conditions need to be more firmly anchored alongside other pain conditions that are afforded respect and compassion. Healthcare providers, schools, the media and brands all have a role to play in educating, challenging perceptions, and enabling women's voices to be heard and respected. We believe the pain dictionary can contribute to this.

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improving women's intimate wellbeing worldwide.

# APPENDIX



## Market specific views

The following section provides some insights regarding the cultural context of women's pain and attitudes towards sex in the individual regions in which research was conducted. **It should be noted, however, that a direct comparative analysis of the regions was out of the remit of this project, and as such, this should not be considered a comprehensive or exhaustive analysis.**

Overall, Europe was the most progressive region researched, although some taboos and shame regarding sex, and particularly painful sex, still endure.

Latin America, the Middle East, Malaysia and Russia, by contrast, are more conservative. Here, religious discourse impacts, as well as more strictly defined traditional gender roles.

In the Middle East, Malaysia, China and Latin America, there is generally less discussion regarding health issues and sex to others, for fear of looking weak. Shame can also potentially be brought upon male partners if women discuss private topics, such as problems with sex or infertility. Women are also expected not to burden others. In China, in particular, pain experiences are played down to others to avoid making them feel uncomfortable, or looking like one is an 'attention seeker'. Across these regions, younger women and more educated and affluent women are generally more likely to push back against these attitudes and seek help.

## A. Latin America

There is a 'machista' culture, where women are meant to be seen, not heard. Culturally, women in Latin America have been taught to be silent and to not disturb. Even though Latinas are characterised as strong women, and usually run the household, socially they must be deferential to men and 'pleasant'.

*"We have a saying that goes, 'When silent you look prettier' - 'Calladita te ves mas bonita'. It's better not to say anything, because who knows, right?"* (Psychologist, Mexico)

This heavily impacts their approach to sharing their discomforts and pain. They don't want to be a burden or be seen as complaining. Women tend to feel ignored, diminished and misunderstood, especially when it comes to pain and sexual health. Their issues or concerns are not openly discussed, even among other women. Topics around sex are filled with taboo and shame. Historically the sexual discourse has come from a male perspective, and male pleasure, leaving women on the sidelines.

*"There was a medicine approved by the FDA, Flibanserin, for sexual desire in women, and there was such a big deal and scandal made about it, that it never came to Latin America. You would take it like Viagra, for women who don't have desire and arousal and we haven't been able to get it in Latin America, it was considered a scandal."* (Sexologist, Colombia)

Expectations regarding femininity halt conversations about women. Culturally, women are set to very high standards and a specific path. Women

should look pretty, be good wives, and be mothers. Sharing too much around concerns, pain, or ailments can fail to achieve this 'ideal woman' image. It can expose an unwanted 'non-femininity'. Female health issues can also be seen as a barrier to bear children and be judged for it, or for sexual encounters with men, an undesirable trait.

*"There's no woman who wants to talk that is hard to lose weight, or that you have more body hair than you should. Or that your hair is falling out. You don't feel comfortable talking about it. It's not who we are supposed to be. It's embarrassing'."* (Advocate with POS, Mexico)

By sharing or talking about these health issues and/or pain, they feel at risk, vulnerable and insecure.

*"What would everyone think, they are going to label me as having something wrong, I am damaged goods, no one wants to feel damaged in any aspect of life."* (Psychologist, Mexico)

*"I am going to be exposed to people learning that I am not having sexual relations with my husband. So, someone could come in and try to offer my husband that which I am not able to give him."* (Sexologist, Colombia)

*"Also, the stigma of having an issue you get labelled as the ill one, the pathological one, 'There is something wrong with her,' like in mental health issues 'She is schizophrenic or has this or that' and no one wants to feel vulnerable."* (Psychologist, Mexico)

There is a cultural belief that pain is part of being a woman, so women

must resign themselves to it. Women's pain is continuously underestimated, specially by men.

*"Men haven't lived with pain like we have. When a man develops, he ejaculates, which is a simple pleasure, it's not like a woman when she has her first period, and it might hurt. Then comes pregnancy, which has its own set of complications, and pain, and bleeding, and spotting, and then delivery which comes with excruciating pain, and then post-partum pain, and breastfeeding. Later there's menopause, and then vaginal dryness, atrophy... She's going to experience pain and be uncomfortable. Men do not experience pain in their life cycles, like women do. So, men usually don't understand, and the patriarchal discourse has just been that we should put up with it."* (Sexologist, Colombia)

*"The woman was born to suffer, to get hurt, to be a mother...she is already predestined, before being born, to what you will be doing with your life. The men always had other privileges, and well, I believe that it would have been good that they would suffer from endometriosis and not us."* (Person with endometriosis, adenomyosis & fibroids, Argentina)

Religious codes condition the conversation with shame and taboos. Catholicism has influenced Latin American culture greatly, impacting how women should behave. Modesty is considered an asset and women are expected to be chaste. Anything connected to the genitals should be kept private, and shame and guilt is associated with these topics. Women are expected to stay a virgin until they reach marriage, and after that, sex is meant for procreation. There is also a

long history of suffering in the Catholic religion and achieving greatness through sacrifice and pain.

Younger women are defying culture standards and breaking their silence. With the help of the Internet and social media, they are taking the bull by its horns. They research their symptoms or conditions, are part of anonymous support groups/chats and arrive at their doctor's appointment with a self-diagnosis.

*"Now young people go online; it is like the bible there. They get on forums and can start speaking about pain in those forums anonymously and can start expressing themselves. This un-stigmatises the fact that my close family labels me as there is something wrong with me. There I can express my pain. There, I may be misinformed, or maybe not, but at least speaking about expressing pain, I can do that".* (Psychologist, Mexico)

*"Teenagers come in with their diagnosis that tell you that they already know what they have, and they need this or that. Furthermore, they reach me online as well. They tell me 'I found out on the internet, and I found that you are going to be able to help me'".* (Psychologist, Mexico)

Advocate women, that have suffered from disabling pain, want to spread the word, inform, and get women the help they need.

*'We need to spread the word and need to say that you can live a better life, change the quality of life, that you can have a timely diagnosis, and if you get a diagnosis when you are 17 years of age and you do not want to think about having a family right there, you*

*can think of freezing your eggs'".* (Advocate with endometriosis, Argentina)

Even though there is still a set, more conservative, female cultural standard to live by, which creates tension between what they want to be versus what they are expected to be, young women realise sex does not need to be taboo. Despite secrecy and shame around sex talk, young women understand they should feel pleasure and are taking steps to feel more powerful. Little by little, through spreading of information and media, they continuously push against it.

*"Many times, they come with the diagnosis. It's interesting, sometimes they come for a consultation and tell me 'Doctor, I think this is what I have'. So, women, little by little are not afraid to talk about their sexuality'".* (Sexologist, Colombia)

For ethnic minorities, lack of equity, access and trust complicate matters even further. Historically, indigenous and black communities have been seen as 'less'. This inequality has had major negative consequences on health, and how indigenous and black communities are treated medically.

*"There is malpractice often because they are not even seen as humans."* (expert in racial disparity, Latam)

This inequality is seen throughout the chain, from access to medical services all the way up to follow-up treatments. It is difficult to reach the right doctor or be referred to a specialist, appointments are short and much is lost in translation, medicine/treatment offered tends to be the cheapest/not best one and needed follow ups are

almost non existents. Long distances, lack of financial resources, less experienced medical staff on rural areas, lack of knowledge/ information, are among the reasons for limited access for these communities. Also, past lived experiences have instilled fear and a lack of trust towards doctors

*"They have been experimented with their bodies historically, their mothers or grandmothers, so they are afraid to go to a doctor and say, 'I have this type of problem'".* (expert in racial disparity, Latam)

## B. Russia

Russian culture is strongly associated with pain and suffering. This is partly influenced by Russian Orthodoxy, but also has roots in the Soviet era and war. There is a cultural belief that one must suffer in order to grow.

*"Russian culture is a culture of pain actually and pain, in our culture, is legitimate and pain is appreciated in our culture. Having pain and expressing pain is a part of Russian culture."* (Semiotician, Russia)

*"I believe that this attitude to pain is a heritage of the Christian culture, where pain was an important part of the path to God".* (Semiotician, Russia)

*"Pain is a heritage of the Soviet period, with its deprivation, hunger and cold."* (Semiotician, Russia)

*"You can only improve and endure through the pain, you can become better through the pain and that's how we now understand pain; it's sacrificial in our culture."* (Semiotician, Russia)

Women's pain is associated with the reproductive system, and, for older women in particular, this is intrinsically linked with shame. Women use euphemisms that men do not understand to discuss taboo subjects.

*"Until recently, periods and everything related with this part of your body that is lower than your stomach was a closed topic, starting from the Soviet Union, women normally didn't discuss it."* (Gynaecologist, Russia)

*"The idea to hide it, it creates a language that men will not understand, it's like to hide it from them, to keep this distance between women and men and to have this whole language available only to women. You can even use these metaphors in public but between women, and even in front of men, because men will not understand what you mean but women will understand, so you can even use these metaphors in public places and you will not be ashamed."* (Gynaecologist, Russia)

However younger women are challenging the perceptions of shame. They are speaking more openly about the subject, periods, and challenging the taboos.

*"Yes, for educated young girls under 30 it's a normal topic to discuss and they can talk openly about it, discuss it, write about it, write about their experience, sometimes they even create self-help boxes at the universities and they put in pads in case your period starts you don't have it in your bag."* (Gynaecologist, Russia)

*"The younger generation is different; they're more reflective on their pain and they will speak about it with*

doctors, they will not be ashamed of their discomfort during periods and they believe that the taboo should not exist anymore.” (Gynaecologist, Russia)

There is particularly low awareness of endometriosis:

“There is the World Endometriosis Association. If you open its website, there is a list of countries, a list of websites all over the world. There are, I’m not sure, two websites in Mexico, a website in Sweden, in Japan, two websites in Australia, in New Zealand. And then you may have an afterthought, ‘Stop, how many people live there? But they have two websites to support.’ Well, I’m not sure, but the British website could be taken as a pattern. I don’t know Spanish, I don’t know normally any other languages which I need to know to evaluate them, but what is available in English is, even in its present variant, which is also not quite a dream, but which is the bar as far from us as any planet, because we have nothing. Absolutely nothing, aside from a clinic that advertises the services of its doctor or a doctor who is a blogger. That is, there are individuals who sell something, medicine or some kind of medical care. But there is not a website, which would be an independent source of information in the field.” (Person with adenomyosis & endometriosis, Russia)

Some women have concerns and fear about seeing gynaecologists, which is formed from past experience. They have a reputation of being rude and judgmental.

“The first time we come across gynaecologists was at school, and these are scary people who talk boorishly to you during a medical

examination, and you feel humiliated and dirty and very disgusting to everyone. I know that my adult friends, who are my age, do not go to a gynaecologist.” (Person with adenomyosis & endometriosis, Russia)

“Well, we’re just scared of gynaecologists. You sit on a chair, they would ask you when you had last had sex, if you had had any abortions. They will treat you rudely.” (Person with adenomyosis & endometriosis, Russia)

Ethnic groups tend to feel greater shame about seeing gynaecologists; whereas young women feel less.

“It’s mostly Muslim women but also Chechens, Tatars, Bashkirs and Armenians and Georgians. – cultural drivers based around shame.” (Gynaecologist, Russia)

“For younger women Slavic women – 18-25 years – it’s really not common to feel ashamed, they’re more afraid of feeling pain during the examination process.” (Gynaecologist, Russia)

### C. China

Pain descriptors in China are very specific, and Chinese people are well-versed in separating out the pain in different elements of the body:

“First you’re asked, ‘Which part of your body feels the pain?’, your response might be, ‘This part of my head’, then they’ll ask, ‘Is it on top of your head, the inside of your head, or is it like a muscle on the side of your head?’ and then they’ll ask, ‘What level of pain do you feel; a little bit of pain, is it very painful, extremely painful or is the pain bearable?’” (Semiotician, China)

“Pain description is very specific, we separate the bone from the muscles, from the chi, or from the feeling, so I can tell you about my pain from different levels. In my experience, in the West it’s more like, ‘My heart feels pain’, ‘My stomach feels pain’, ‘My back feels pain.’” (Semiotician, China)

Culturally, pain can be a sign that healing is taking place.

“The Chinese massage is very hard...we kind of like it because we know the moment we feel the pain that it’s already in healing, if we don’t feel the pain in the therapy it’s not enough to heal it.” (Semiotician, China)

But as a culture, negativity regarding pain is socially sanctioned, as discussing it could make others feel uncomfortable. Negative experiences of pain are only discussed with a doctor or a very close family member. However, it is more acceptable for women to show pain than men.

“I don’t believe that the Chinese are open to talk about the negative or the pain side of the experience, they tend to focus on the bright side, or the happy experience; people would be offended if you’re too straight about their shortcomings or the negative things.” (Semiotician, China)

“There is a gender difference; if you’re a man it’s not very manly to express your pain too much but it’s more acceptable in society for women to express their pain, either physically or emotionally.” (Semiotician, China)

Although women will talk about period pain, discussion about sex and painful sex is largely taboo. There is a lack of sexual health education.

“I also want to emphasise that sex-related topics are generally suppressed or kind of taboo in China, even for the younger generation, sex education is still poor, so it doesn’t help women to get to know their own bodies and to protect themselves. There’s still shame around sex – there are some younger women who enjoy their bodies but I’m talking generally – but I think it relates to why, when we talk about pain, especially.” (Gynaecologist, China)

“There’s actually a really good system for women in China but it’s not well used; in China women can have free birth control pills and condoms but not everyone takes advantage of it because they feel ashamed about it and some people don’t know about it at all, so health education is something that could be improved.” (Gynaecologist, China)

“When it comes to sex-related pain it’s still only talked about privately because of the taboo of sex.” (Semiotician, China)

Conversations around gynaecological pain are also frowned on, unless among very close friends/family, as they are linked to sex organs. As a result, there is some shame around seeing a gynaecologist.

“There is some level of suppression in this type of pain in particular because it’s sex organ related; you’re suppressed, you’re silent, you don’t tend to express these feelings publicly, or very strongly, maybe with your close friends or your mum or your doctor, but not to the public because it’s sexual organ related, so it’s kind of private, even friends don’t talk about it that often.” (Gynaecologist, China)

*"I'd say over 80% of women feel some degree of shame in talking about it and even talking to a gynaecologist, yes". (Gynaecologist, China)*

Shame is less prevalent among more affluent women who visit private clinics, however. Typically, they have travelled outside of China and have different perspectives regarding gynaecological health.

*"I work in an international clinic and most of the patients are from a similar socio-economic background and it seems better for them, they don't feel ashamed, they're more open to talking about all kinds of issues, working in the public hospital is more difficult, I need to talk to them and encourage them to talk about things." (Gynaecologist, China)*

*"They have more resources, they've had the chance to travel, they know how to take care of themselves, especially those who've lived or studied outside of China and may have seen gynaecologists abroad, they have more choice." (Gynaecologist, China)*

#### **D. Malaysia**

Malaysia is ethnically and religiously diverse and has one of the highest income disparity rates between rich and poor amongst Southeast Asian nations. In tune with the diversity in the population, access and attitudes towards women's healthcare vary. Religion has a big impact, with Muslim and some Hindu populations being more conservative in attitudes towards women and sex. There are also variations according to urban and rural populations, education levels and age.

Overall society is conservative though, and attitudes towards girls and women are protective. Female pain is normalised, and endometriosis is usually dismissed by mother/aunties as being painful periods, which will pass after childbirth. Male sexual dissatisfaction (due to their wife's pain) and concerns around their wife's fertility are the key drivers for women seeking medical help. Pain is less of a driver, and women find it difficult to express their pain.

In general, there are barriers talking about sex, except for the most educated middle and upper classes who tend to be more open. Taboos around sex / genitals impact on women presenting to a specialist and create embarrassment, fear or silence. Religious taboos make women very guarded about trusting a doctor if they are sexually active before marriage. There is particular shame and fear for women who have been abused.

Women find it difficult to talk about their bodies. They often do not give detail on their problems, and it has to be coaxed out, starting with general questions, moving on to the bladder, gut health then progressing to gynecological pain. Many women refer to their genitalia or other parts of their reproductive system as 'down there'.

*"My patients generally just don't know the right words to describe anything – for example, you'll be surprised, they don't know the appropriate word to describe their genitals! – so, 'I'm having pain in my genitals', we have that in various words – excuse my language, but if someone says 'pussy', it's bad, so they don't say it, they say 'down there' – when someone says 'down there',*

*even your legs are down there, you know!? – so I tell them to point to where exactly it is and then they start to point, so I tell them, 'It's okay, you can tell me', so I have to coax them." (GP specialising women's conditions, Malaysia)*

Women with vaginismus/painful sex often bear in silence and only seek help when their partners express resentment. Men often don't understand this is a condition, they think women are 'spoiled', or just don't like them. Women often self-diagnose and may buy vaginal dilators from the internet – which can be dangerous if there are underlying conditions.

With endometriosis, women tend to self-diagnose (using the Internet) and come to the clinic mostly worried they will not have children. Women rarely have privacy with their doctor/ gynaecologist. 20% are accompanied by their husbands, many are accompanied by mothers/ aunties.

There is high usage of traditional medicine, especially among the older generation who are less trusting of Western medicine.

*"Like in China, there is some recourse to traditional massage, herbs and other traditional remedies according to the respective traditions (Indian, Chinese, Malay...) to manage pain, which meets nature-based new age approaches in private holistic clinics for the most privileged patients". (Physiotherapist, Malaysia)*

*"There was a clinical study run by certain major hospitals in Malaysia to check at the level of chronic pain in the Malaysian population and you'd be surprised, about 7% suffer from chronic*

*pain...Their first port of call are things like meditation or acupuncture, the Chinese love acupuncture, Malays and Muslims go for the traditional massage, meditation, the Indians love it, so they tend to go towards all that for the pain management because they feel that Western medicine and the doctors don't really help them." (GP specialising in women's conditions, Malaysia)*

Religious and spiritual discourse links pain to punishment for misdeeds, which can lead to women believing it is God's will and something they must endure.

*"One of the things is to help them cross the barrier, to get them to understand that they're not being punished, that they haven't done something wrong and that they don't deserve to get pain." (Physiotherapist, Malaysia)*

Gynaecological conditions are rarely treated holistically. Gynaecologists tend to focus on issues requiring surgery or infections – which require bio-medical treatment. They rarely refer to physiotherapists.

#### **E. Middle East**

Awareness of gynaecological conditions is not high in the Middle East, especially in Saudi Arabia. Women may seek out information from media in other countries.

*"I used to always watch Lebanese and Egyptian TV shows where they spread awareness about endometriosis and diseases, here in KSA they don't do that! And even if they did shows for awareness they will only talk about sterility and promote a certain doctor only, they only talk about IVF without*

*explaining to people what that means because they refuse to think that their cases requires IVF, and I was one of those people until I got educated about the topic and others should as well.” (Person with Endometriosis, Saudi Arabia)*

Younger women tend to actively seek more for help, and the ability to be more financially independent aids this.

*“We used to notice this before, but now since I have been in practice for around 30 years I could say that 20 years ago the girls were hesitant to visit a gynaecologist because they thought that it means something wrong if they visited a gynaecologist. While now the girl comes alone from the university after searching online.” (Endometriosis Expert/Gynaecologist, ME)*

*“Now, she has become financially independent and economically, so this gave her more freedom to seek medical advice for any illness and not only the pain or any chronological issue. She is free to do that alone and this is something good.” (Endometriosis expert/Gynaecologist, ME)*

As with Malaysia, the key issues that women seek help pertains to men’s lack of sexual satisfaction (due to the woman’s pain), or concerns around infertility. These issues can cause public shame for men. This can put a strain on marriages and women are fearful that their husbands will seek divorce – which is borne out in reality. Polygamy can also mean that husbands find another wife.

*“I feel very nervous. As you know, when sex relations between husband and wife is good and your husband feels satisfied about having sex, your*

*life would be good and both your husband and you would feel calm. The husband would not behave in a way against you. Sometimes, they might say something like ‘I have to look for another wife,’ and even if he is just joking it would be bad.” (Person with Endometriosis, ME)*

*“I was mentally tired and afraid, my husband was also mad and this was actually a bad experience and bad marriage because I broke up with my husband since he wasn’t understanding at all and he used to tell me that I’m afraid of what people will think and he was always angry and nervous which made me suffer even more!” (Person with Endometriosis, ME)*

*“When my husband knew that I will have to go through an IVF he thought that this would be a hard thing so he gave up on me and got engaged to another woman!” (Person with Endometriosis, ME)*

Owing to the shame/honour cultural codes of the Middle East, women can sometimes feel more comfortable talking to a doctor about gynaecological pain than family members.

*“I used to feel embarrassed to tell my mum or sister but not the doctor, I used to speak to her very comfortably. Because I felt like she will understand me since she has seen many similar cases.” (Person with Endometriosis, ME)*

*“I tell the doctors everything and do not feel shy about it, but with my friends and sisters I do not speak about the private things.” (Person with Endometriosis, ME)*

However, there is a lot of embarrassment and shame associated with talking about sex and sexual pain, even to professionals.

*“They are open, but with certain things such as pain during having sex, I have to ask them this question. I ask, ‘Do you experience pain when having sex?’, ‘Do you have pain in a specific position?’. I ask them the question and they start to open up.” (Endometriosis expert/gynaecologist, ME)*

*“When he asks me about my sexual intercourse I feel shy to answer him, I wouldn’t answer honestly.” (Person with Endometriosis, ME)*

*“He’s also very religious which makes me shy to speak to him, sometimes I even change the subject.” (Person with Endometriosis, ME)*

## **F. Europe**

In the countries we researched – UK, France and Sweden – there is relatively less shame regarding gynaecological conditions.

The general background in France is that of a moderately progressive society within the Western European context; legislation is progressive and there is free public debate around many societal issues. But there is a feeling that the medical establishment is quite conservative and patriarchal, despite the prevalence of women gynecologists and GPs, and that societal prejudice around a number of women’s issues, specifically periods, women’s pain and sexual pleasure, remain. For instance, it is very much accepted for French women to work, drop their kids off at a crèche during daytime and achieve self-fulfillment in

their careers, but less acknowledged that sexual pleasure is equally important to them as it is to men. Pain or suffering still is seen as a ‘woman’s lot’ in certain areas. Semioticians speaks of enduring expressions like “you have to suffer to be beautiful” and a number of demeaning expressions for women who i.e complain about pain (douillettes, femmelettes, chochottes) and same used for men judged to exaggerate pain.

LGBTQ+ Black, Asian and mixed heritage groups face particular issues and many harsh barriers. There has been a drive to educate regarding endometriosis. There is a clear departure in France since about 2014. A number of associations have launched public information campaigns around endometriosis (e.g. Endotime ‘Periods are natural, pain is not’), there has been more education on this topic and other women’s gynecological issues in professional circles, and young women are well informed through the internet and associations. Besides the media campaigns, events such as endometriosis sponsored runs have spread knowledge and permitted others (husbands, family friends) to get engaged and have served as an important lever to promote the topic of period pain within labour rights/ the corporate world.

Sweden is quite progressive, although, again, barriers exist. There is little shame in seeing a gynaecologist although women still feel some shame during the actual consultation.

*"Sometimes we still feel that women are reluctant to go to a gynaecologist because they're reluctant to talk about the problem they're having."*  
(Gynaecologist, Sweden)

In the UK, women's pain conditions have historically been ignored in society and women have felt pressure to keep silent. More work has been done recently to try to bring women's pain into the public eye and validate it, breaking down the shame and stigma traditionally associated with it. The All Party Parliamentary Group on Endometriosis was launched in 2018 to create more awareness in parliament. This group actioned research into women's experiences of endometriosis, culminating in a report in 2020:

*"This report is a long-overdue account of how those with endometriosis throughout the UK deserve better when it comes to their healthcare. It provides recommendations on how care and support need to be improved, and what practical changes the Government can make to ensure the voices of the 1.5 million people with endometriosis are heard."* Sir David Amess MP, Chair, All Party Parliamentary Group on Endometriosis<sup>78</sup>

A debate regarding (the lack of) workplace support for women with endometriosis also took place in parliament in 2019, alongside a Work Foundation report that called for the perceived taboos around women's reproductive health to be 'shattered'. High-profile women have spoken out about their struggles with endometriosis recently, including Emma Barnett, journalist and presenter on Women's Hour on BBC Radio 4,

whose recently published book discusses her experiences seeking a diagnosis over 21 years. Author, Dame Hilary Mantel, has also talked publicly about her struggles with endometriosis, that led to the breakdown of her marriage.

There is still some level of taboo and stigma surrounding sex in the UK, despite it being quite progressive. Sex is also embedded within notions regarding what makes a body 'sexy' and what a sexual experience should be like. Painful sex can therefore be seen as a failing, and shame ensues, both in terms of not satisfying a partner but also not being a 'whole woman'.

*"Lots of people just feel like they're really on their own with it and there's lots of taboo around speaking about it [painful sex]...There's just so many things that we're led to believe about sex, what sex should look like, and so when you don't feel like you measure up to that, or you're not having the kind of sex that you see on television, like on a late night Channel 5 film and things like that, then you feel, 'It must be me, I'm the thing that isn't quite right.'"* (Person with dyspareunia, UK)

*"I want the word for 'emasculate' but for females, it 'affects your femininity', it makes you feel like 'not a full woman'...I think that the language surrounding that is a lot to do with 'failure' and a lot to do with 'feeling like you don't work' and this feeling that you're 'turned off' and you're 'not sexual.'"* (Person with dyspareunia, UK)

Women can feel almost frivolous to seek help from doctors, especially as heterosexuality normativity is often assumed and some doctors still

consider men's sexual satisfaction is most important.

*"I guess the idea is that it doesn't really feel like an illness, it doesn't really feel like a disease, it feels quite audacious to go to your GP and say, 'I would like sex to feel nice, please ... thank you.'"*  
(Person with dyspareunia, UK)

*"They always worried about how it was affecting the man and how that then impacted on the relationship, not, 'Oh, it's affecting you, how does that impact the relationship?'"* (Person with dyspareunia, UK)

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