Period Pain or Endometriosis - What should HPE teachers know and teach about endometriosis

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What is endometriosis and should it be taught in schools?

In this article we argue that as teachers of health and physical education in Aotearoa New Zealand, we need to improve our knowledge and education about menstruation, period pain, and endometriosis and in doing so address some of societies misconceptions about female sexual health. That is, we need to become more informed as a society, and we believe that school health and physical education is a good place to start this process. The reason for our call, is that endometriosis can be the cause of serious physical and mental health issues for many females, generally and more specifically, adolescent girls in our schools. In Aotearoa New Zealand 1 in 10 young females suffer severe pain from endometriosis (also known as endo) yet little is known or taught about it in our health education classes (Bush, et al., 2020).

What is endometriosis?

“Endometriosis is the growth and presence of tissue histologically similar to endometrium outside the uterine cavity” (Rizk et al, 2003. p.7). This is a full body disease and as of right now there is no cure. For many females’ endo causes severe and often debilitating pain. However, most of society would simply believe it to be ‘bad period pain’ but would not know the medical reasons or the social and emotional implications for those who suffer from it. In fact, many see it as being normal for girls and even think that they should just get used to the pain and symptoms.

There are four stages of endometriosis – minimal, mild, moderate and severe, however, these stages are not based on symptoms or pain. (Rizk, et al., 2003). The four stages are determined by the depth of the implants, scarring and locations of the implants. These stages are only determined when someone is diagnosed with endometriosis through laparoscopic surgery (Rizk, et al., 2003). According to East-Powell (2020), stage one involves a small number of superficial implants that are mainly located within the peritoneum, which is the membrane that forms the lining of the abdominal cavity that covers the abdominal organs. Stage two has slightly deeper implants than stage one but there is a chance of scaring. Stage three is where endometriosis implants can spread towards the rectum, uterus and on one ovary. The implants are also deeper and there can be visible scarring. Lastly, stage four is the most widespread stage with many deep implants as well as large cysts on at least one ovary, along with scarring on the lining (Bush, et al. 2020).This stage can also be found in other areas including the bowel, appendix and bladder.

According to Bush, et al (2017), 176 million girls and females worldwide are affected by this disease during their reproductive years. This works out to be 1 in 10. Unfortunately, many women with endometriosis will have fertility problems as scar tissue and adhesions can attach to ovaries or compress the fallopian tubes making it difficult for eggs to travel to the uterus among many other complications. On average, adolescent girls with endo will go for 7 visits to their GP before getting a gynaecologist referral (Bush, et al, 2017). The reason for this is a combination of entrenched social norms and a lack of education of general practitioners. Many adolescent girls think the pain, nausea, and fatigue theyare experiencing are just part of growing up as a girl and do not share their symptoms with others or go to their general practitioner. When they do go to their GP they are often told that it is normal to have painful periods, irregular bleeding, and other symptoms and the GP will often prescribe high pain meds or suggest the contraceptive pill. The outcome of this is that there is usually a delay of 8 or more years from onset of symptoms to a definitive diagnosis (Bush, et al, 2017). The following stories from two young endometriosis suffers exemplify these social and educational issues:

> Girl A: *I started experiencing symptoms when I was about 16, really painful periods, abdominal cramping, sciatic pain, bloating and because our period education at school wasn't very good, I always just thought it was normal. I would have to take days off school during my period as I couldn't get out of bed and sometimes when I did go to school I would pass out or vomit due to the pain. I went to about 4 different general practitioners and they all told me it was normal; I was being overdramatic or to just suck it up as it is part of being a girl. I have now had my laparoscopic surgery and have received an official endometriosis diagnosis.*

> Girl B: *Endometriosis symptoms have been a part of my life since my first period at the age of twelve. Throughout intermediate and high school, I would have many sick days and leave school early due to the pain. I saw the doctor many times over the years and the solution I was given was to begin taking a combined contraceptive pill. Skip past eight years of pain, different kinds of issues arising and many different contraception methods, I read 'How to Endo' by Bridget Hustwaite and self-referred myself to a gynaecologist to find out the real underlying issue. I am now on the waiting list in the public system to see a gynaecologist and then be accepted to the waiting list for laparoscopic surgery to get an official diagnosis for endometriosis. I had a transvaginal ultrasound that came back stating I have a polycystic ovary on my left ovary.*

Polycystic Ovary Syndrome is a hormonal condition that affects 1 in 5 girls (Health Navigator New Zealand, 2021). This is a condition where certain types of cysts grow on the ovaries and can cause disruptions to a girl's menstrual cycle, as well as causing weight gain, skin and hair changes, along with other symptoms. Women with PCOS also ovulate less often than other women which means they may struggle with falling pregnant.

Collectively, these are compelling reasons why we need to better understand endo and help adolescent girls and others manage the severe health conditions associated with it..

What are the symptoms of endometriosis?

There are many symptoms of endometriosis and some females will have to deal with many of them but others may only have a few or no symptoms. Some of the most common symptoms include chronic pelvic pain, severe dysmenorrhea (painful period), dyspareunia (painful intercourse), abnormal bleeding, fatigue and bloating. Although these are some of the most common symptoms there are many more such as dyschezia (painful bowel movements), diarrhoea, reoccurring urinary tract infections, dysuria (painful urination), fatigue, abnormal menstrual bleeding, depression or anxiety (Hustwaite, 2021).

Despite the large number of possible symptoms, endometriosis is hard for GPs to detect. It is commonly misdiagnosed as being irritable bowel syndrome or pelvic inflammatory disease. According to Seaman, et al. (2008), these diseases have symptoms that cross over, including abdominal pain, abdominal bloating, tenderness and dyspareunia. Misdiagnosis can occur because endometriosis can grow on the stomach, bowel and deep into the pelvis causing many similar symptoms.

Dysmenorrhoea is another disease that commonly leads to a misdiagnosis. Harada (2013) says that the symptoms for dysmenorrhoea include lower abdominal cramping that stops a women from completing her day to day tasks . Some women can have dysmenorrhoea but not have endometriosis. Due to lower abdominal cramping also being one of the main symptoms of endometriosis many doctors diagnose women with primary dysmenorrhoea. According to Harada (2013), “primary dysmenorrhoea refers to menstrual pain without underlying pathology whereas secondary dysmenorrhoea is menstrual pain associated with underlying pathology” (p.81) such as endometriosis. Because some doctors do not fully understand endometriosis and its symptoms, when they hear a female patient complain of painful periods they can assume that she has primary dysmenorrhoea without following up with further questions or doing a pelvic exam to determine if it is primary or secondary dysmenorrhoea.

Treatment and coping with endometriosis.

Endometriosis is very difficult and can be expensive to get a diagnosis and treat. Therefore coping with endo is a necessary requirement for many young females. This is why coping mechanisms are an important part of educating our youth about this disease. As many females experience symptoms every day, they need ways to help minimise the pain. A few examples are heat therapy (wheat bag or hot water bottle), pain relief medication, baths, slow walks, eating an anti-inflammatory diet and and hydration.

Laparoscopic surgery is the only way to officially diagnosis endometriosis. This surgery is performed under general anaesthetic, and requires the surgeon to insert gas inside the stomach, before a thin telescope is inserted through the belly button to see what is happening inside. This process enables the surgeon to see where the endometriosis is and how many implants there are. When they find tissue that contains endo, they insert tools through small incisions in the pelvic and abdominal area and take allall of the tissue, then send some of it for testing to determine it is definitely endometriosis (Huswaite, 2021).

When removing the implants of endo, there are two main types of surgery used. Excision and Ablation. Excision surgery is the best option to remove the entire implant as they will be removed from the roots. But excision surgery is more invasive and the surgeons that perform this type of surgery need to undertake more training and study to be qualified enough. Even after surgery, it is not guaranteed that endometriosis will not come back but there is less chance of reoccurrence after excision surgery than ablation surgery , which is the second option (Fogelson, 2020).

Ablation surgery is more accessible for surgeons as it requires less training and study than excision. In ablation surgery the surgeon uses heat energy to burn/vaporise the endometriosis implants. Ablation surgery is used to burn the tops off without burning the roots and scar tissues, therefore following ablation surgery there is more chance of endometriosis growing back. This technique is believed to have better results for females in stages 1 or 2 because the implants are superficial compared to the deeper implants of stage 3 and 4(Fogelson, 2020).

So why should the topic of endometriosis be taught in our high schools?

Endometriosis should be taught in health education in our high schools because, as debilitating as it can be, our young female students typically do not have knowledge about this disease. As two recent Aotearoa secondary school graduates we did not hear about endometriosis, menstrual cycles or anything to do with female sexual health throughout our five years of secondary schooling. So we are now advocating for change because we believe that too many adolescent girls, who are experiencing severe period pain symptoms don't know that it is not just a bad period, and they don't know about or have access to the right information about endometriosis to get the help they need. Endometriosis is affecting many girls in many high schools, causing not only physical pain but also emotional stress which in turn may have educational and social impacts as many girls miss school altogether or opt out school based activities simply because of the pain and discomfort caused by endometriosis.

It is also important to recognise the need for boys to know more about this as they are surrounded by girls who may be experiencing this chronic disease. These boys need to have an understanding to why girls feel the way they do when suffering from severe period pain, PMS, and other symptoms that are involved in this full body disease and other diseases that are associated with female sexual health. In teenage communities, we often will hear of boys saying, 'awe she's in a bad mood, must be on her period'. But this shows that there is no understanding or sympathy for what these girls may be going through.

According to the New Zealand Curriculum (2007), in the learning area of health and physical education (HPE), the seven key areas taught to our young adolescents include "mental health, sexuality education, food and nutrition, physical activity, sport studies, outdoor education and body care and physical safety" (p.22). The closest subheading to female sexual health would be body care because it is more likely to include sexual health but after looking at different standards from NZQA we found nothing to do with our bodies, how they work or what is normal and what is not. This shows the urgent need for more engagement from health and physical education teachers in this area.

As teachers of HPE, we can use our platform to pass this knowledge on to our adolescents' as they grow and develop. While also targeting to eliminate endometriosis suffering for many of our adolescent female students. Further information is available from Endometriosis NZ, which is a national charitable non-government organisation that creates health initiatives and ground-breaking programmes for schools, workplaces and hospitals.

To Conclude:

Endometriosis is a whole-body disease defined as the presence of endometrial like tissue outside the uterine cavity that affects 1 in 10 women around the world. It can take upwards of 8 years to diagnose. Many women don't even know that they have this disease and suffer for years after being told they 'are being overdramatic' or 'it's just part of being a girl'. This female health issue has been stigmatised for many years but in recent times more awareness has been raised in the hope of faster diagnosis to stop it having such a debilitating effect on females lives. These are the reasons why we believe that through better health education in schools we can decrease the stigma around female sexual health and increase the understanding about this significant health issue.

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