Developing community support services to empower the Waikato Endometriosis community

Research Summary

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Summary of Research

> *'Endometriosis is a horrible thing. You can do all you can do to control it but it always takes over your life.' **
>
> *'People don't seem to understand because it isn't something you can see.'*
>
> *'There definitely needs to be more understanding of endometriosis in the community and more support from the government and health providers.'*

Endometriosis is a debilitating disease affecting an estimated 10-15% of women of reproductive age. Many suffer for years before being diagnosed because the wide range of disparate symptoms, including pain, heavy bleeding, fertility problems, immune system issues and mood swings, make the disease difficult to recognise. Normalisation of painful periods by many women and health professionals alike is also an impediment to diagnosis. While there is no cure for endometriosis, it can however be well managed through a range of comprehensive surgical and medical strategies, once diagnosed.

This research, carried out by SHORE and Whariki Research Centre and Insight Endometriosis (formerly known as Endometriosis Waikato), explored the experiences of women in the Waikato with endometriosis and looked at levels of access to services. Insight Endometriosis is a not-for-profit organisation empowering women with endometriosis through community support, information and education and by raising awareness in the wider community. Of the estimated 20,000 Waikato women (one in ten) who have endometriosis, approximately 300 are registered with Endometriosis Waikato. The SHORE and Whariki Research Centre, School of Public Health, Massey University has a team of researchers with an international reputation in the field of social, health and evaluation research.

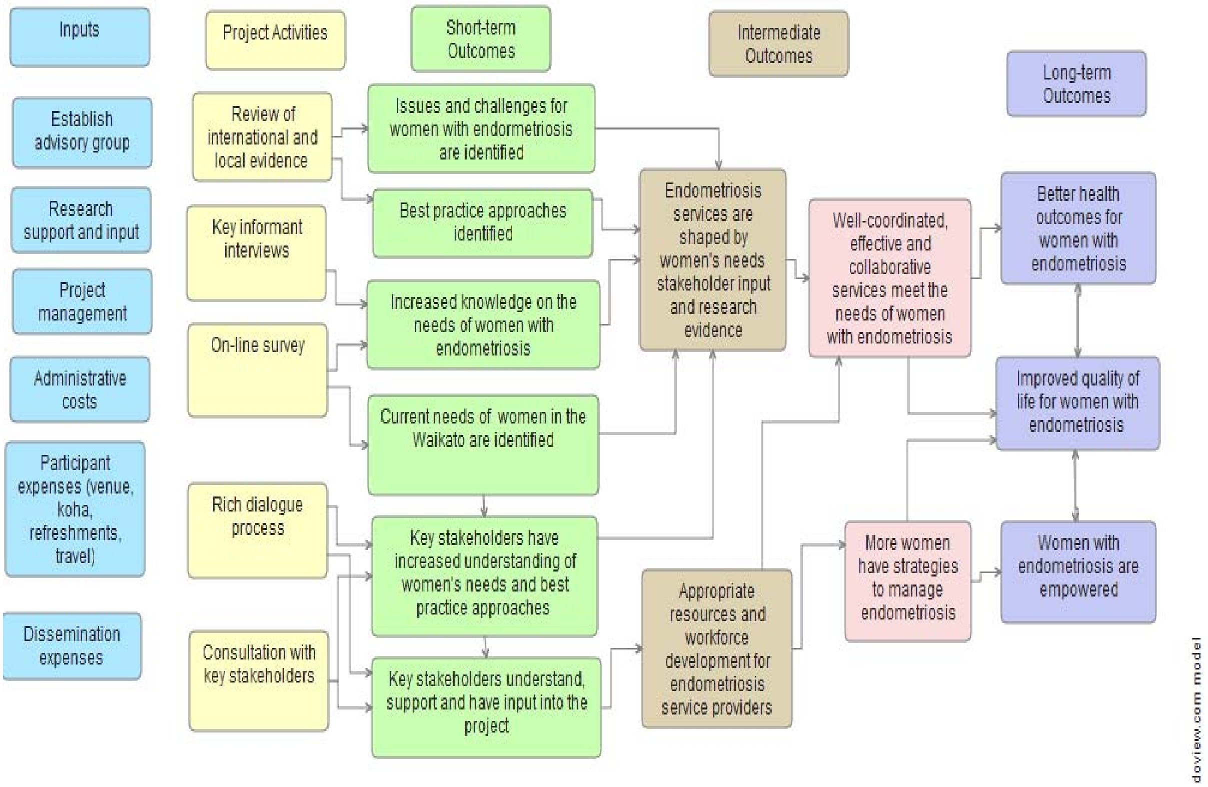
Women shared their experiences in an on-line survey and follow up in-depth interviews, while interviews with health professionals helped assess the availability of services in the Waikato for women with endometriosis and barriers they faced in accessing treatment. The online survey was completed by 132 women (main geographic areas were Hamilton City, Cambridge and Morrinsville) and 10 key informant interviews were conducted with health service providers and women with endometriosis.

A review of the international literature on endometriosis helped establish 'best practice' protocols and a Rich Dialogue Process (RDP) was held with health professionals to share and reflect on research findings. The study was funded by a Lotteries Commission Community Sector Grant.

A logic model developed for the research project (see Figure 1 below) shows research activities and the expected outcomes of the project.

*Unless otherwise specified quotes are from Waikato women involved in the research project.

Figure 1. Developing community support services to empower the Waikato Endometriosis Community logic model



The overarching research questions that emerged from the logic modelling were:

- What are the experiences of women with endometriosis?
- What are the needs of the endometriosis community in the Waikato area?
- What are the appropriate services and resources to meet the needs of the endometriosis community in the Waikato area?

Research findings

For most women their first endometriosis symptoms were experienced during adolescence and began with the onset of menstrual pain, heavy bleeding or both. Many reported experiencing a long and arduous route to diagnosis. While some women felt treatment had been successful, others felt nothing had helped in alleviating debilitating symptoms.

Endometriosis symptoms

The endometriosis symptoms reported by women included pain, fatigue, immune system problems and allergies, mood problems, fertility problems and bowel problems. By far the most commonly reported symptom was pain.

'Pain is one of the largest symptoms…and pain-related interference with daily living.'

Normalisation of pain

For many women the pain they experienced prior to diagnosis of endometriosis was often discounted or normalised by themselves, family members, teachers, employers and general practitioners, leaving them feeling disillusioned, full of self-doubt and unsupported.

'I have always had problems since my early teens, but thought it was all part of being a woman and just lived with it.'

Life impacts of endometriosis

Findings indicated endometriosis impacts on many aspects of both younger and older women's lives. The most commonly reported life impacts were mood difficulties, time off work or study and keeping up with day-to-day activities. Very few women described having understanding employers.

'It brings a lot of physical and emotional distress for about two weeks every month so I only feel normal half the time. The fatigue and high pain levels leave me distracted and with difficulty concentrating on things I enjoy, including work.'

Women aged over 35 years (48%) were significantly more likely to report experiencing fertility problems than young women (31%).

'I've had fertility problems and had to get pregnant using IVF.'

'It has robbed me of having children and I would have loved to have had at least one.'

The long road to diagnosis

While most women (65%) sought help within two years of experiencing endometriosis symptoms and some were diagnosed promptly (laparoscopy is the only method for a conclusive diagnosis) others reported a torturous journey to diagnosis and treatment, with delays and misdiagnoses. Some were prescribed pain medication and were told their period pain was normal; others were diagnosed with irritable bowel syndrome and suspected appendicitis. Being told by health professionals that their symptoms were psychological was also a common experience. Women reported multiple visits to GPs and were likely to see more than one GP for help with their symptoms before being referred to a specialist.

'I didn't know I had it until after a hysterectomy in 2009 at the age of 45. I'd been misdiagnosed for years.'

Treating and managing endometriosis symptoms

Once referred to a gynaecologist, women were more likely to receive appropriate treatment. The most commonly reported option for managing or treating endometriosis was surgery for the removal of endometriosis. Painkillers or oral contraceptives provided partial relief for some, but had no effect on pain for others. Some women pursued complementary and alternative therapies such as acupuncture, immunotherapy, medical herbalism, natural progesterone and other lifestyle factors such as improving nutrition and participating in physical activity. There is no definitive 'cure' for the disease. Says one gynaecologist:

'There are a lot of problems with endometriosis…there's a common belief that if [you] have surgery for endometriosis that's the end of it…the figures that I quote are about 80% of people are symptom free for four or five years afterwards, but by 10 years almost everyone has got it back.'

On-going management of endometriosis

Given the chronic nature of endometriosis, most women reported they were managing symptoms in an ongoing way. They spoke of needing better educated and more understanding health professionals, particularly GPs, who took their symptoms seriously, shorter hospital waiting times, more affordable services and education for adolescents.

Options and Ideas for the future

- Symptoms of pelvic pain should alert GPs and other primary care professionals to a possible diagnosis of endometriosis. This could result in the reduction of diagnostic delay – and perceived dismissive attitudes of GPs towards women presenting with endometriosis could be improved, resulting in a more positive experience for women.
- Improved GP knowledge of presenting symptoms should lead to appropriate referral to secondary care and effective diagnosis and treatment.
- Collaboration with local gynaecologists is needed to develop treatment guidelines, best practice models and pathways of care, similar to those for diabetes.
- Integration of community services with Integrated Family Health Centres (IFHC's) – such as enabling bookings for education appointments within IFHC practices – need to be investigated; and IFHC staff need to be well-informed about endometriosis and pathways to care.
- A pilot programme taking a pro-active screening approach, with women and teens encouraged to discuss symptoms such as period pain and referred on to gynaecologists if appropriate, should be considered to reduce diagnostic delays.
- An on-going evaluation process, using the current research project as a benchmark, would track changes such as reductions in diagnostic delays and improvements in quality of life outcomes