Women’s experiences of osteopathic care whilst living with endometriosis

Maadi Dalgliesh Waugh

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Declaration

Name of candidate: Maadi Dalgliesh Waugh

This thesis entitled *Women’s experiences of osteopathic care whilst living with endometriosis* is submitted in partial fulfilment for the requirements for the Unitec degree of Master of Osteopathy

Principal Supervisor: Dr Mikki Williden
Associate Supervisor: Maureen Perkins

Candidate’s declaration:

I confirm that:

This thesis represents my own work;

The contribution of supervisors and others to this work was consistent with the Unitec Regulations and Policies.

Research for this work has been conducted in accordance with the Unitec Research Ethics Committee Policy and Procedures, and has fulfilled any requirements set for this project by the Unitec Research Ethics Committee.

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Candidate Signature: Date: 26/11/2019

Student number: 1446213
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Abstract

Purpose of the study: At present, more than 3% of women and girls in New Zealand (NZ) experience symptoms of endometriosis. The purpose of this study was to investigate the experience of a sample NZ women who considered osteopathy to be effective in dealing with their symptoms of endometriosis and to relate the findings to the literature regarding the success of complementary and alternative medicine for the management of endometriosis. This study sought first-hand responses from participants in order to help provide insight into how to improve the management and support available to women as they manage this highly complex condition. The study also sought to establish a case for further research into osteopathy as supplementary management. The thesis presents the findings of the study and suggests implications for osteopaths and other health professionals who provide treatment and advice for women with endometriosis. It concludes with providing suggestions for future research regarding the direct effects of osteopathic treatment on symptoms of the disease.

Methods: Using a qualitative descriptive approach this thesis explored the experiences of a convenience sample of NZ women diagnosed with endometriosis who had each experienced osteopathy as part of their management for the condition. Interviews were conducted with four women aged 30-50 years, who had a laparoscopy-confirmed diagnosis of endometriosis. All of the women had included osteopathy as a strategy for managing the symptoms of endometriosis. The interviews were recorded and transcribed verbatim. Data analysis followed the steps of the thematic analysis described by Braun and Clarke (2006).

Findings: The main themes that emerged from the interviews included: the value of osteopathic treatment for increased quality of life by empowering participants and encouraging self-management; the importance of osteopathic characteristics such as understanding the significance of patient-centred care and having compassion, building trust, making time, and encouraging relaxation; and the positive impact of osteopathy on the physical self through touch, treatment being a positive experience, and the holistic method of both assessment and treatment.
**Discussion:** The participants expressed their past and current ‘battle’ with the physical and psychological symptoms associated with endometriosis and how these impacted on quality of life. All participants had accepted that they would not find a cure for their endometriosis, instead, they each sought support and guidance to manage the associated symptoms rather than relying solely on pain medication. The findings suggest that the contributing factors to a successful treatment outcome are multifactorial and do not solely depend on the technical skill of the practitioner. Rather, a successful treatment includes a complex and dynamic relationship between the patient and practitioner which is built on trust and compassion.

**Conclusion:** The findings of this study justify further research examining the role of osteopathy as an option for the management of endometriosis including both physiological and psychological symptoms associated with endometriosis.

**Keywords:** Endometriosis, chronic pelvic pain, osteopathic care, experience, complementary and alternative medicine.
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List of Abbreviations

CAM  Complementary and alternative medicine
NZ   New Zealand
ESHRE The European Society of Human Reproduction and Embryology
CPP  Chronic pelvic pain
QoL  Quality of life
HRQoL Health related quality of life
DIE  Deep infiltrating endometriosis
OMT  Osteopathic manipulative technique
UREC Unitec Research Ethics Committee
CPSP Chronic post-surgical pain
GP   General practitioner
SF   Short form
EHP  Endometriosis health profile
PDI  Pain and disability index
VAS  Visual analogue scale
SOPA Survey of pain attitudes
PCS  Pain catastrophising scale
CHAPTER ONE – INTRODUCTION

Definition of Endometriosis

Endometriosis is a chronic disease affecting the uterus and is frequently diagnosed in women of child – bearing age (Juhasz-Böss et al., 2014). It is defined by the presence of functional ectopic endometrial glands and stroma-like tissue found outside the uterus in several sites which are either intra-peritoneal or extra-peritoneal. Sites include the abdomen, ovaries and fallopian tubes (Borghese, Zondervan, Abrao, Chapron & Vaiman, 2017). A proportion of patients with endometriosis are asymptomatic. However, the majority have clinical manifestations of varying intensity which can include dysmenorrhea, dyspareunia, chronic pain (CP) and subfertility (Petta, Matos, Bahamondes & Faúndes, 2007). It is currently understood that endometriosis is a proliferative, oestrogen-dependent disorder involving central neurological sensitisation, similar to CP syndrome (Pabona, Simmen & Nikiforov, 2012; Johnson & Hummelshøj, 2013).

Epidemiology

It is estimated that 10 – 15% of women worldwide are affected by endometriosis, with 3% of women within New Zealand (NZ) having been diagnosed with the condition (Flores et al., 2008, Endometriosis New Zealand, 2016). Endometriosis may be present in up to 60% of women reporting painful periods (Brown, Crawford, Allen, Hopewell & Prentice, 2017), and 35% – 50% of women with pelvic pain and infertility (Sasson & Taylor, 2008). However, it has multiple appearances and varied symptoms, which contribute to a commonly experienced delay in its diagnosis. Endometriosis is only reliably diagnosed with laparoscopy, and diagnostic accuracy is further increased when a biopsy is performed (Hsu, Khachikyan & Stratton, 2010). This suggests that the true incidence of endometriosis is largely unknown as the availability of laparoscopy is often limited (Avid, Live & Ritts, 2001; Zondervan, Yudkin & Vessey, 2001; Gylfason et al., 2010).

The natural history of the disease has not been well defined as many adolescent girls report painful periods which can be a symptom of several gynaecological concerns.
Furthermore, almost a quarter of women with endometriosis are asymptomatic (Bulletti, Coccia, Battistoni & Borini, 2010). It is therefore difficult to diagnose endometriosis without invasive laparoscopic testing (Hickey, Ballard & Farquhar, 2014). Although endometriosis was first diagnosed more than 100 years ago (Batt, 2011), and symptoms were documented over 2000 years ago (Nezhat et al., 2012), current knowledge of its pathogenesis, evolution, and the pathophysiology of its major symptoms remains unclear (Rogers et al., 2009).

**Complementary and Alternative Medicine**

Complementary and alternative medicine (CAM) have been defined as therapeutic medical and healthcare practices which are not considered to be a part of conventional medicine (Groden, Woodward, Chatters & Taylor, 2017). While there is little published research regarding the success of CAM for the management of endometriosis there is sufficient reporting in non-academic journals to suggest that many women with endometriosis have found CAM therapies helpful for dealing with associated symptoms (Endometriosis New Zealand, 2017). Fisher et al. (2004), and Rubinstein et al. (2010), have reported that CAM, including the use of supplements and manual therapy, are used by 84% of women who require musculoskeletal pain management. These reports also indicate that 87% of those patients indicated that they would use CAM again due to the lack of side effects.

Many support groups and forums established for endometriosis sufferers provide references to articles which report positively on the use of physical therapy, nutrition/diet, acupuncture, homeopathy, and other treatments (Endometriosis New Zealand, 2017). In NZ there are particular CAM therapies that are statutorily regulated and regulated under the Health Practitioners Competence Assurance Act 2003, including chiropractic and osteopathy (Ministry of Health, 2019). Osteopathy is a therapeutic, structural treatment based on musculo-fascial structures and their influence on somatic signs and symptoms (Sillem et al., 2016). While osteopathy is among the CAM which has played a part in treating endometriosis there have been few researched accounts of its use in managing symptoms, and how osteopathic care may benefit women with endometriosis.
Structure of the Thesis

Chapter Two of the thesis provides background information on endometriosis, including a review of the literature describing endometriosis, its origins and its manifestation as a serious condition. Chapter Three continues to explore literature relevant to the experience of endometriosis, literature surrounding its management, and the role of osteopathy in the management of the disease’s symptoms. Chapter Four discusses the methodology of the study, including qualitative and descriptive research methods and its application during this research project. It also includes information about the participants within this study and the ethical considerations that were undertaken to ensure patient safety and confidentiality. Chapter Five presents the findings of this study and discusses them in relation to relevant literature. The final chapter, Chapter Six, presents an evaluation of the contribution of this project. It concludes with suggestions for future research regarding the possible benefits of osteopathic treatment on the symptoms of endometriosis.
CHAPTER TWO – BACKGROUND INFORMATION

This chapter provides background information on the anatomy of the endometrium, the aetiology of endometriosis and the treatment currently available. It briefly explores the practice and philosophy of osteopathy and the literature available relevant to the experience of osteopathic care.

Anatomy and Physiology of the Human Endometrium

The uterus is an inverted pear-shaped organ which is hollow and has thick muscular walls. It can be subdivided into three parts; the fundus, which is the dome shaped portion superior to the uterine tubes, the central body, and the inferior narrowing cervix which opens to the vagina.

Histologically the uterus is composed of three layers: the perimetrium which laterally becomes the broad ligament and anteriorly surrounds the urinary bladder, the myometrium which is the middle layer of strong smooth muscle fibres which are associated with labour, child birth and dysmenorrhoea, and the endometrium which is the innermost glandular layer which lines the uterus and maintains the patency of the uterine cavity. The endometrium is highly vascularised and experiences morphologic and functional changes that are closely associated with the cyclic release of sexual hormones.

The endometrium has multiple components to it including the singular inner-most layer of columnar epithelium and the stroma which rests upon it. The stroma is a connective tissue which creates the structure of the uterus and contains blood vessels and nerves which thicken in response to hormonal influences.
Cyclic Endometrial Changes

The primary functions of the human endometrium are to allow the implantation of an embryo and provide the mechanisms that are needed for the clearance of tissue and returning to homeostasis during menstruation (Young & Loy, 2005).

The endometrium’s cyclic structural changes are regulated by ovarian oestrogen and progesterone. During menstruation, the endometrial lining undergoes rapid degeneration and regeneration. The cells of the endometrium increase and become thicker to prepare for housing a fertilised egg. This relationship between the ovarian hormonal stimuli and the change of structure and function in the endometrium has been considered one of the most sensitive indicators of the hypothalamic-pituitary-ovarian hormonal axis (Wynn, 1977).

Aetiology

The aetiology of endometriosis is currently uncertain (Johnson & Hummelshoj, 2013). Associations have been made with hereditary, environmental, epigenetic, and menstrual factors. These may contribute to symptoms such as dysmenorrhoea, chronic pelvic pain (CPP) and infertility which have been found to affect a woman’s physical, mental and social wellbeing (Kennedy et al., 2005). Many theories have been proposed to explain the pathogenesis of endometriosis, such as retrograde menstruation, coelomic metaplastic and induction theories, however these all remain inconclusive. Many theories have also been suggested to explain the aetiology of endometriosis (Hogg & Vyas, 2018). The more common theories include the retrograde menstruation theory, coelomic metaplastic theory, induction theory, immunological theory, archimetra theory, and a heredity theory. These theories are briefly described below.

Retrograde menstruation theory

Retrograde menstruation is the original and most widely accepted theory. Also known as Sampson’s theory, it proposes that endometriosis occurs during menstruation due to the retrograde or reflux flow of apoptotic endometrial cells
through the fallopian tubes into the pelvic cavity (Sampson & Foot, 1925; Sourial, Tempest & Hapangama, 2014). Since this theory was introduced in 1925, experimental evidence has been provided to support this hypothesis (Giudice, Evers & Healy, 2012). Halme, Hammond, Hulka, Raj and Talbert (1984) supported this theory by observing and reporting menstrual blood in the peritoneal fluid of up to 90% of healthy women with patent fallopian tubes during the perimenstrual time of the cycle. However, Sasson and Taylor (2008) highlight that retrograde menstruation occurs in the majority of women with patent fallopian tubes and not all of these women have endometriosis. This finding may indicate that the relationship between patent fallopian tubes and endometriosis is correlative rather than causative.

Coelomic metaplastic theory

The metaplasia theory proposes pelvic endometriosis may be derived through a metaplastic process derived through endometriotic lesions that arise by a process of metaplasia from the ovarian surface epithelium (Matsuura, Ohtake, Katabuchi & Okamura, 1999). The metaplasia occurs secondary to an inflammatory process or hormonal influences. It is suggested that hormonal or immunological abnormalities initiate normal peritoneal tissue to transdifferentiate abnormally into ectopic endometrial tissue (Gruenwald, 1942; Burney & Giudice, 2012). This theory may explain the occurrence of endometriosis outside of the pelvic cavity in the absence of menstruation (Doty, Gruber, Wolf & Winslow, 1980; El-Mahgoub & Yaseen, 1980). The metaplasia theory is still supported for ovarian endometriosis (Vercellini, Vercellini, Viganò, Somigliana & Fedele, 2013). However, it appears that the sources surrounding this theory are dated and controversial as they fail to account for the occurrence of extra-pelvic endometriosis (Davis & Goldberg, 2016).

Induction theory

The theory of induction is an extension of the Metaplastic theory, with hypotheses that endometrial differentiation of undifferentiated cells is stimulated by one or several endogenous, biochemical or immunological factors. This theory assumes that dying endometrial tissue releases specific substances from the endometrium which are then transported by blood and lymph to form endometriosis in different parts of the body (Vinatier, Orazi, Cosson & Dufour, 2001; Giudice et al., 2012). However, Maruyama and Yoshimura (2012) highlight that the inducing factors and mechanisms
responsible for the differentiation remain to be elucidated, which makes the acceptability of this theory problematic.

**Immunological theory**

It has been suggested that there could be an association between the presence of endometriosis and altered cell-mediated and humoral immunity (Dmowski, Steele & Baker, 1981). The immunological theory suggests that the survival of ectopic, endometrial implants could be due to an abnormal immune response (Riccio et al., 2018). The immune system’s role in endometriosis has been extensively studied and immune anomalies have been identified. However, it is unknown whether these immune anomalies are a cause or a result of endometriosis (Berkkanoglu & Arici, 2003).

**Archimetra theory**

The archimeta is the glandular and stromal part of the endometrium. According to Leyendecker, Kunz, Noe, Herbertz and Mall (1998) endometriosis primarily arises from this specific section of the endometrium. They suggested that the cause of endometriosis could be related to the tissue-specific inflammatory response and repair to trauma. The subsequent interaction of the ovarian endocrine system and a non-organ-specific paracrine system are locally activated in processes of tissue injury and wound healing. This process involves the regulatory functions of oestradiol and results in the local production of oestradiol and the involvement of the oestrogen receptor beta. This process leads to alterations of the archimetra and may be considered a contributor to the development of the disease (Gerhard Leyendecker, Wildt & Leyendecker, 2011). More recently Ibrahim et al (2015) observed microtrauma in the endometrial-myometrial which is consistent with this theory.

**Heredity theory**

There is increasing evidence that endometriosis is hereditary (Kennedy, 1999). Studies have associated genetic polymorphisms with the development of endometriosis (Falconer, D’hooghe & Fried, 2007; Albertsen, Chettier, Farrington, Ward & Ferreira, 2013). In addition, familial studies of endometriosis have revealed a polygenic/multifactorial inherited component to the disease (Hansen & Eyster, 2010) and the increased risk of disease development when it has occurred in close relatives.
(Kennedy, 1997, 1999; Tempfer, Schneeberger & Huber, 2004). However, environmental, epigenetic and menstrual factors play a large role in the disease development (Falconer et al., 2007; Albertsen et al., 2013).

**Summary**

The heterogeneity of the above theories indicates that the aetiology of endometriosis is complex and multifactorial, and may involve hormonal, genetic, immune, and environmental components. Correlations have also been explored with comorbid conditions, autoimmune disease, allergies and intolerances (Matalliotakis, Cakmak, Matalliotakis, Kappou & Arici, 2012; Smorgick, Marsh, As-Sanie, Smith & Quint, 2013; Klein et al., 2014; Surrey et al., 2018) as the prevalence of developing comorbid conditions were significantly higher among women diagnosed with endometriosis when compared to women without (Surrey et al., 2018). The complex aetiology of endometriosis is a significant component of the challenge in providing a diagnosis and treatment choice, whether this treatment be within mainstream medical contexts or CAM.

**Experience of Endometriosis**

**Signs and symptoms**

Endometriosis typically occurs in the pelvis, most commonly in the ovaries and surrounding areas covered with peritoneum such as the pouch of Douglas and the uterosacral ligaments (Murphy, 2002). The most common symptoms associated with endometriosis include dysmenorrhea, dyspareunia, CPP and infertility. However, 20-25% of patients are asymptomatic (Bulletti, Coccia, Battistoni & Borini, 2010).

Dysmenorrhea is the symptom most often associated with endometriosis, particularly if it is severe and does not respond to nonsteroidal anti-inflammatory medication or the oral contraceptive pill (Murphy, 2002). The pain is usually reported to begin prior to the onset of menses. Additionally, it can become chronic and may be experienced throughout most of the menstrual cycle. Pain is often referred to the rectum or lower back particularly if the rectovaginal or uterosacral ligaments are involved (Murphy, 2002). Dyspareunia is also associated with rectovaginal and uterosacral ligament attachment onto the uterus or ovary by adhesions.
While there is a clear association between endometriosis and subfertility, it may or may not present with additional symptoms. In women with endometriosis, pelvic pain and dyspareunia can affect sexual activities and intercourse, which can then compound fertility problems (De Ziegler, Borghese & Chapron, 2010).

**Diagnosis**

Diagnosis is most often based on the laparoscopic evaluation of the location and extent of the endometriotic adhesions (Tinneberg et al., 2014). Endometriosis can be divided into four stages of severity. Stage I represents minimal pelvic implants whilst stage IV represents implants which have affected many pelvic organs with possible distortion and adhesion (American Society for Reproductive Medicine, 1997). There appears to be no known correlation between the symptoms experienced and stage or severity of disease (Fedele, Parazzini, Bianchi, Arcaini & Candiani, 1990; Ling, 1999; Gopalakrishnan Radhika, Chawla, Nanda, Yadav & Radhakrishnan, 2016).

The diagnosis of endometriosis is often delayed (Nnoaham et al., 2011; Klein et al., 2014; Moradi et al., 2014). Delays in diagnosis may be explained by the nonspecific nature of symptoms and the unavailability of specialised diagnostic modalities (Arruda, Petta, Abrão & Benetti-Pinto, 2003; Petta et al., 2007; Stefansson et al., 2002; Vinatier et al., 2001). Stigma and embarrassment surrounding the condition and lack of awareness of symptoms have also been suggested to contribute to delays and misdiagnosis (Culley et al., 2013; Moradi et al., 2014).

**Treatment and Management of Endometriosis**

**Routine endometriosis care in New Zealand and internationally**

Saraswat (2018) has reported that there is currently no known cure for endometriosis. Despite this, there is a wide variety of treatment options available for the management of symptoms and treatment of pain including analgesic, hormone medication and surgery (Dunselman et al., 2014). However, standard treatment choices for endometriosis are relatively expensive, with the most common method of treatment such as surgery remaining controversial. Neither medical nor surgical options provide long term or universally acceptable relief for patients (Sourial et al., 2014) and some
can have severe adverse effects such as surgery risks, weight gain, acne, flushing and loss of bone mineral density particularly if used over long periods (Endometriosis New Zealand, 2016; Kumar & Sharma, 2014; Moradi et al., 2014; Ribarich & Segundo, 2016; Schrager, Falleroni & Edgoose, 2013; Soliman, Yang, Du, Kelley & Winkel, 2016; Valle & Sciarra, 2003). Vercellini, Viganò, Somigliana and Fedele (2014) recommend that management is to be personalised depending on patient’s needs and decision-making should be shared between the patient and clinician.

**Standard treatment**

**Analgesic**
Analgesic drugs are commonly recommended as a simple first-line treatment for women with endometriosis. They are often used in an attempt to alleviate pain as they are readily available and have few side effects when taken as prescribed (Brown et al., 2017; Kennedy et al., 2005; Sinaii, Cleary, Younes, Ballweg & Stratton, 2007). However, there is a lack of conclusive evidence on their effectiveness in reducing pain associated with endometriosis (Allen, Hopewell & Prentice, 2005; Allen, Hopewell, Prentice & Gregory, 2009; Brown et al., 2017).

**Hormonal**
Oral contraceptives such as progestogens and anti-progestogens can be used clinically for symptoms associated with endometriosis (Dunselman et al., 2014; Rice, 2002). An alteration of oestrogen and progesterone receptors in endometriotic tissue is recognised as the trigger for a change in hormonal function. Treatments such as hormonal medication which manipulate the endocrine system can have positive effects on relieving dysmenorrhoea and possibly dyspareunia. However, there may also be unpleasant side effects including breakthrough bleeding, nausea, headaches, an elevated risk of venous thromboembolism, a loss of libido, cutaneous reactions, sodium and fluid retention leading to weight gain, breast tenderness and a rise in blood pressure which has the potential to lead to many other health complications (Halis, Mechsner & Ebert, 2010). As there is no overwhelming evidence to support one hormonal treatment over another, it is important that individual and informed treatment plans are created through collaboration between the informed patient and practitioner (Dunselman et al., 2014).
**Surgery**

Surgery is currently the method of choice for treating endometriosis with laparoscopy being considered the highest standard for surgical treatment (Halilis et al., 2010). Surgical treatments available include ablative techniques and excision techniques. Excision techniques such as laparoscopy and laparotomy aim to relieve symptoms whilst conserving reproductive function (Bedaiwy & Barker, 2012). Brown et al., (2017) explain that depending on the severity, practitioners can perform a hysterectomy through the removal of one or both of the ovaries (Oophorectomy). Laparoscopic surgery has been associated with less pain, shorter hospital stays and quicker recovery as well as better cosmetic outcomes, making it the preferred option compared with open surgery (Dunselman et al., 2014).

Surgical removal of deep endometriosis has been associated with reducing endometriosis-associated pain and has contributed to the improvement of a patients’ quality of life. However, this is a short-term solution for many women (De Cicco et al., 2011; Meuleman et al., 2011a, 2011b). Whilst a follow-up appointment one year after surgical treatment revealed pain relief in between 50% and 95% of patients (Practice Committee of the American Society for Reproductive Medicine, 2008), recurrence of the condition after surgery is reported in approximately 40-45% of patients five years after the primary surgery (Evers & Dunselman, 1995; Garry, 2004). Reoperation occurs in over half of individuals with endometriosis, with about 27% requiring three or more surgeries (Cheong, Tay, Luk, Gan & Li, 2008).

**Summary**

Endometriosis is a chronic gynaecological disease which affects women from different age groups worldwide. Current knowledge of its pathogenesis, evolution and pathophysiology of the major symptoms remains unclear. However, the symptoms associated with endometriosis such as dysmenorrhea, CPP and infertility have been found to negatively affect women’s physical, mental and social wellbeing. There is conclusive evidence that physiological pain associated with endometriosis has an effect on all aspects of a woman’s biopsychosocial sphere and severe pain has been the most important issue identified by patients. There is currently no known cure for endometriosis and controversies exist regarding the best method of treatment. Neither
medical nor surgical options provide long term or universally acceptable relief for patients and some have severe adverse effects.
CHAPTER THREE – LITERATURE REVIEW

This chapter explores the literature surrounding the subjective experience of living with endometriosis, management of chronic pain (CP), complementary and alternative medicine (CAM) and osteopathy and what has previously been regarded as important aspects of a healthcare encounter.

Search Process

An electronic database search was conducted to identify relevant literature. Databases included EBSCO Host, ScienceDirect, Google Scholar, Scopus, PubMed/Medline, and ProQuest. Multiple searches through these databases were made using a combination of the following keywords: endometriosis, patients, management, experience, CAM, osteopath, osteopathic manipulative technique, physical, emotional, meaningful, beliefs.

Due to the limited number of studies addressing osteopathy and endometriosis specifically, a broader search was undertaken which included chronic pain (CP), chronic pelvic pain (CPP), manual therapy, physical therapy, healthcare and orthodox medicine. The reference lists of retrieved articles were scanned for additional relevant articles. From this search, articles were retrieved and the abstracts scanned to assess for relevancy. When deemed relevant, the full text of the article was retrieved to be included in the literature review. A total of 155 articles were included. Because of the minimal recent research pertaining to endometriosis the search expanded to CPP and CP as they have the same underlying mechanisms including changes in the central nervous system (Apkarian, Bushnell, Treede & Zubieta, 2005; Tracey & Bushnell, 2009; Brawn, Morotti, Zondervan, Becker & Vincent, 2014; Kaya, Hermans, Willems, Roussel & Meeus, 2013).

This literature review explores the subjective experience of endometriosis including the effect it has on health-related quality of life and why this is important. It also includes a discussion on current management of CP and CPP, highlighting the important aspects of the clinical encounter, CAM therapy and osteopathy and what has previously been regarded as important aspects of a healthcare encounter.
The Experience of Endometriosis

Endometriosis appears to be strongly associated with CPP (Ozawa et al., 2006). Pain is a very subjective experience which can be challenging for clinicians and researchers. There is increasing evidence that the individuals meaning of pain is of the utmost importance and can greatly influence a person’s psychological state and quality of life (Basler, Grzesiak & Dworkin, 2002).

In CPP, neurological changes are observed in the dorsal horn of the spinal cord, which results in neurogenic inflammation, hyperalgesia, and a lower sensory threshold for pain (Wesselmann, 2001). The external presence of CP may reveal very little of the internal world of the sufferer (Kirkham, Smith & Havsteen-Franklin, 2015). This elusiveness could pose a potential barrier to understand the lived experience of CP generally.

Endometriosis tends to afflict women of reproductive age with the average age of diagnosis at twenty-eight (Bloski & Pierson, 2008). Between 70-90% of teenagers will experience symptoms of pain during menstruation (Klein & Litt, 1981; Andersch & Milsom, 1982; Johnson, 1988; Wilson & Keye, 1989; Hillen, Grbava, Johnston, Stratton & Keogh, 1999; Banikarum, Chako & Kelder, 2000) accompanied by a number of other physical, psychological and emotional symptoms. With this in mind, distinguishing dysmenorrhoeic symptoms associated with normal menstruation and symptoms from pathological disease such as endometriosis can be difficult (Parker, Sneddon & Arbon, 2009). This highlights the importance of referral of teenage girls with menstrual pain for further investigation.

It has been reported that 47% - 74% of adolescent girls presenting to physicians with severe menstrual or pelvic pain with no response to non-steroidal anti-inflammatory drugs or the oral contraceptive pill, will be suffering from endometriosis (Bullock, Massey & Gambrell RD, 1974; Goldstein, De Cholnoky & Emans, 1980; Laufer, Goitein & Bush, 1997; Reese, Reddy & Rock, 1996). With the diagnosis of endometriosis commonly overlooked in primary care, patients have expressed the unnecessary suffering and reduced quality of life (QoL) that such uncertainty can cause (Harvey, 1970; Denny, 2004; Ballard, Lowton & Wright, 2006).
Endometriosis is considered disabling, with significant effects on a women’s everyday life, including social relationships, sexuality and mental health (Siedentopf, Tariverdian, Rücker, Kentenich & Arck, 2008). CP is known to have an impact on mood, self-esteem, and can manifest feelings of guilt, shame, and grief/loss (Burke, Mathias & Denson, 2015). Endometriosis has been described as being overwhelming and affecting a woman’s well-being by stealing her “dreams, career, relationships, friends, and the right to a decent life” (Wang, 2004 p. 1). This can then lead to social isolation (Mellado et al., 2016) and can negatively affect emotional well-being (Sepulcri Rde & do Amaral, 2009).

Studies have highlighted the strong association between endometriosis and pelvic pain and infertility (Giudice and Kao, 2004). It has also been shown that endometriosis-related pain can correlate negatively with health related quality of life (HRQoL) (Souza et al., 2011), sexual functioning, the quality of relationships with partners (Ferrero et al., 2005), mood (Sepulcri Rde & do Amaral, 2009), work and social functioning (Fourquet et al., 2010).

A woman’s psychological state has shown to have a major role in determining the severity of endometriosis related symptoms such as pain. Women who suffer from endometriosis report high levels of distress, anxiety, depression and other psychiatric disorders (Laganà et al., 2017). Symptoms such as CPP can also significantly affect a woman’s emotive functioning (Laganà et al., 2017). This appears to be a vicious cycle where negative emotional state and physical pain reinforce each other. This could be explained by the neuroendocrine–immune disequilibrium presented, whereby the inflammatory nature of endometriosis may lead to the proposed ‘sickness response’, associated with the vicious cycle (Tariverdian et al., 2007; Siedentopf et al., 2008; Nasyrova et al., 2011).

It should also be noted that Facchin et al., (2015) highlighted that women with asymptomatic endometriosis may not report impaired HRQoL and mental health. In this study, it was revealed that dependent variables (such as mental quality of life, physical quality of life, anxiety and depressive symptoms) did not vary between patients with asymptomatic endometriosis and the healthy controls. These findings suggest being diagnosed with endometriosis, when asymptomatic, is not necessarily
associated with poorer quality of life and psychological health. Also, the occurrence of pain symptoms is one of the primary reasons to seek healthcare in the New Zealand (Petrie, Faasse, Crichton & Grey, 2014). This suggests that if women are not experiencing pain associated with endometriosis, they may be less likely to seek medical care and therefore less likely to receive a diagnosis.

**Importance of health related quality of life**

Health related quality of life (HRQoL) is defined as an individual’s perceived physical and mental health over time (Centers for Disease Control and Prevention, 2019), and addresses the psychological, social and physical components of a particular health condition during and following an intervention (Greer, 1984). HRQoL has been conceptualised into physical, functional, psychological, social, spiritual and sexual domains of disease (Roomaney & Kagee, 2016). In recent years, more interest has grown surrounding endometriosis and the impact on QoL (Ferreira, Bessa, Drezett & de Abreu, 2016).

The measurement of HRQoL in patients with endometriosis has been often quantified using various instruments, the most popular includes the Short Form 36 (SF-36), Short Form 12 (SF), and Endometriosis Health Profile-30 (EHP) Questionnaire (Bourdel et al., 2019). However, Camfield, Crivello and Woodhead, (2009) argue that qualitative methodologies are more likely to reflect participants worldviews by “recognizing the contextual, subjective and non-material dimensions of human experience” (p. 8).

Both qualitative and quantitative studies conclude that symptoms of endometriosis such as dyspareunia, dysmenorrhea and infertility substantially and negatively impairs HRQoL physically, psychologically, and socially (Young, Fisher & Kirkman, 2015; Roomaney & Kagee, 2016). However, the impact of compounding factors such as age, income, symptom severity and care-seeking behaviour upon HRQoL is relatively unknown (Nnoaham et al., 2011; Vercellini et al., 2013).

In drawing conclusions from these studies, it is important to consider the low response rates and relatively small sample sizes (Young, Fisher & Kirkman, 2015; Ferreira, Bessa, Drezett & de Abreu, 2016; Roomaney & Kagee, 2016). One larger
study by Graaff et al., (2013) assessed to what extent do the management of endometriosis and the symptoms that remain after treatment affect the quality of life in women with the disease. Questions obtained from the World Endometriosis Research Foundation (WERF) and Global Study on Women’s Health, along with the SF 36 version 2 (v2) were used to survey 931 women who suffer from endometriosis-associated symptoms even though their endometriosis has been managed in tertiary care centres. Of the 931 participants, endometriosis had affected work in 51% of the women and affected relationships in 50% of the women at some time during their life. Dysmenorrhoea was reported by 59%, dyspareunia by 56% and CPP by 60% of women. QoL was decreased in all eight dimensions of the SF 36 v2 compared with norm-based scores from a general US population (all p = 0.01). This study demonstrates that with conventional management women still suffer from frequent symptoms associated with endometriosis and as a result their quality of life is significantly decreased.

In another larger study Steven Simoens et al., (2012) used a questionnaire-based survey to measure costs and quality of life in 909 women with endometriosis-related symptoms. To register the evolution of health-related quality of life over time the EuroQol-5D instrument was filled in by women at the beginning of the study, at 4 weeks and again at 8 weeks. The EuroQol-5D covers five areas associated with HRQoL, including mobility, self-care, daily activities, pain/discomfort and anxiety/depression. In terms of HRQoL, women who suffered from symptoms associated with endometriosis reported, problems with pain/discomfort and depression/anxiety. Further responses to the EuroQol-5D indicated that 16% of women reported issues with mobility, 3% reported issues with self-care, 29% reported issues with activities of daily living, 56% experienced pain and discomfort, while 36% experienced anxiety/depression. This finding is consistent with a literature review (Gao et al., 2006a,b) and with recently published papers (Fourquet et al., 2011; Nnoaham et al., 2011), concluding that endometriosis impairs health-related quality of life especially in the domains of pain, psychological and social functioning.

The reduction of QoL in patients with endometriosis could be associated with the complex nature of the aetiology, the patient’s response to interventions, the severity of daily pain experienced by the patient, the presence of dyspareunia and fertility status (Minson et al., 2012).
Management of Chronic Pelvic Pain

As endometriosis is strongly associated with CPP (American College of Obstetricians and Gynecologist, 2010), osteopathy may be beneficial for women who have endometriosis (Tettambel, 2005; 2007). However, there is little research to date that explores this hypothesis. The success of osteopathic treatment for a chronic condition such as chronic pelvic or low back pain could potentially be transferred to treating chronic endometrial symptoms. However, there is little research to date that explores this possibility.

Chronic pain is defined as an “unpleasant sensory and emotional experience associated with actual or potential tissue damage” (Merskey & Bogduk, 1994) and is a complex interplay of physical, psychological, social, and occupational factors (Petit, Fouquet & Roquelaure, 2015). CP is a frequent complaint of patients in primary care, however, patients report low satisfaction with CP care (Green, Wheeler, Marchant, LaPorte & Guerrero, 2001; Upshur, Luckmann & Savageau, 2006). It is common for CP patients to hold strong beliefs that the pain they are experiencing is due to tissue damage (Darlow et al., 2012; Darlow et al., 2013; Bunzli, Watkins, Smith, Schütze & O’Sullivan, 2013; Lin et al., 2013). These negative and misinformed beliefs have potential to lead to the development and maintenance of CP. The ‘fear-avoidance model’ is based upon the original works of Lethem et al., (1983), Philips, (1987) and Waddell et al., (1993), but has since been reviewed and validated by Vlaeyen and Linton (2000). This model describes a behaviour pattern showing that when pain is perceived as threatening it can result in pain-related catastrophic thinking, fear and anxiety. This behaviour and thought patterns have been proposed to lead to avoidance behaviour, disability, and a vicious cycle of CP (Leeuw et al., 2007). Therefore, pain management should be adapted to consider the type of pain as well as the overall prognosis for the patient (Russo & Brose, 1998).

CP is complex, and is known to be influenced by biological, psychological and social factors (Asmundson & Katz, 2009; Choinière et al., 2010; Dillie, Fleming, Mundt & French, 2008; Gaskin & Richard, 2012; Phillips & Schopflocher, 2008). CP management has become multimodal and multidisciplined with an emphasis placed
on the use of a range of strategies aimed at maximising pain reduction and improving health-related QoL (Gatchel & Okifuji, 2006; Ospina & Harstall, 2003; Scascighini, Toma, Dober-Spielmann & Sprott, 2008). There is increasingly widespread acceptance of the biopsychosocial model for management of chronic pain (Foster, 2011), as strong evidence is presented that intensive multidisciplinary biopsychosocial and functional rehabilitation improves function and QoL in chronic pain patients (Guzmán et al., 2001).

A study by Schliessbach et al (2013) investigated the prevalence and potential determinants of central hypersensitivity associated with CP in order to guide management of CP patients. They tested 464 CP patients for generalized hypersensitivity. They concluded from this study that generalized central hypersensitivity is not present in every patient. Generalized central hypersensitivity was significantly associated with the female gender (p < 0.001), pain duration (p = 0.017) and pain syndrome (p = 0.021). This research supported that an individual assessment is required in order to detect altered pain processing so that patients can be offered an individually tailored mechanism-based treatment.

CPP, often described as persistent, noncyclic pain lasting longer that 6 months, is perceived to be associated to structures related to the pelvis (Speer, Mushkbar & Erbele, 2016). CPP can lead to significant medical, social, and economic consequences, relationship issues, lost work productivity, and larger health care costs. CPP in females is a complex pain syndrome that affects many women worldwide (Grace & Zondervan, 2004). CPP can be caused by not only gynaecological conditions, but gastrointestinal, urological, musculoskeletal, neurological and psychiatric conditions (Thomas, 2018). The somatic pain syndrome and neural sensitization is typically associated with other functional somatic pain syndromes such as endometriosis (Stratton & Berkley, 2011), and mental health disorders such as depression (Piontek et al., 2019).

A population based study performed in NZ by Grace and Zondervan, (2004) used a random sample of 2,261 women, generated from the New Zealand (NZ) Electoral Roll. This study revealed that CPP prevalence rate was 25.4% (95% CI 22.8-27.9) and half of those women reporting CPP remained undiagnosed. Surprisingly, only one-third of NZ women (34%) reported no form of CPP at all. These results highlight the
importance of public education surrounding the diagnosis of CPP and the clinical awareness of CPP needed by health-care professionals. CPP has been described by participants as impacting on all aspects of a woman’s being. In addition to the physical symptoms of CPP, there is well-documented literature in the European Association of Urology Guidelines 2013 and the Royal College of Obstetricians and Gynaecologists guidelines (2012), that patients also experience associated negative psychological, behavioural, cognitive and sexual consequences (Royal College of Obstetricians and Gynaecologists. 2012; Engeler et al., 2013). In both guidelines experts express the need for interdisciplinary and multidisciplinary care. This is reflected by a review by Baranowski, Lee, Price and Hughes, (2014) which aimed to review the key points and controversies around the British Pain Society's CPP patient pathway map which focused on the initial non-specialist management of patients with CPP.

Psychology based treatments have been reported to be beneficial when complemented with medical or surgical management (Tripp, Nickel & Katz, 2011; Cheong, Smotra & Williams, 2014). However, the quality of the evidence was low or moderate, as in most cases evidence was derived from single small studies and there were no randomized controlled trials with longitudinal follow-up.

A qualitative analysis which explored the views of patients with complaints about their CP care experiences revealed that patients feel more satisfaction when healthcare professionals used patient-centred approaches to establish goals and treatment plans (Upshur, Bacigalupo & Luckmann, 2010).

**Important Aspects of the Clinical Encounter**

*Patient-centred care*

Research has shown that a patient-centred model of care is associated with more treatment compliance, positive patient–provider relationship, and an increase in treatment satisfaction (Fischer et al., 1999; Hirsh et al., 2005; Masi, White & Pilcher, 2002; O’Brien et al., 2010).
Patient-centred care can be defined as “providing care that is respectful of, and responsive to, individual patient preferences, needs and values, and ensuring that patient values guide all clinical decisions” (Institute of Medicine, 2001).

Patient-centred medicine was originally introduced in 1969 by Michael and Enid Baling. It was introduced in the medicine as an ‘alternative’ way of thinking, taking into account the emotional, spiritual and relational dimensions of patient presentation (Balint, 1964; Holmström & Röing, 2010). Patient-centred care has for decades been a major focus for research and health policy developments. Since 2001, patient-centeredness has been considered vital for enhancing quality of care in health care systems (Wolfe, 2001), as it acknowledges and respects the entirety of the patient, considering the individuality, values, ethnicity, social background and education of the individual.

Patient-centred care can transform a health-care professionals’ role from one based on authority to one of partnership, solidarity, empathy, and collaboration (Epstein & Street, 2011). Epstein & Street, (2011) surmise that patient-centred communication contributes to the patient feeling understood and involved, which is directly associated with patient satisfaction and ultimately improved health outcomes (Street, Makoul, Arora & Epstein, 2009; Epstein & Street, 2011). Research and anecdotal evidence shows that people who have gained the knowledge, skills, and confidence to manage their health effectively are more likely to adopt the behaviours needed for positive health outcomes and care experience (Hibbard & Greene, 2013).

A study performed by Bertakis and Azari, (2011) collected data from 509 patients randomly assigned to either family physicians or general internists who were second and third year residents. Physician practice styles were analysed by coding the videotapes using a modified version of the Davis Observation Code and then measures of visit-specific satisfaction and healthcare resource utilization were gathered from participants. Patient-centred care was observed more often with family physicians (p = 0.0003) caring for healthier, more educated patients. During the initial visits the patient-centred practice style was positively associated with higher patient self-reported physical health status (p = 0.0328), higher patient knowledge (p = 0.0050), and non-smoking status (p = 0.0108). These results suggest that patient-
Personal behaviour change is very important in improving health and obtaining successful disease management (Higgins, 2014). Health care professionals can play an integral role in facilitating positive behaviour changes by developing and enhancing patients’ knowledge, beliefs, and self-regulation skills (Ryan, 2009; Náfrádi, Kostova, Nakamoto & Schulz, 2018). A study by Náfrádi, Kostova, Nakamoto and Schulz, (2018), highlighted several aspects of the doctor–patient relationship that contributed to positive patient outcome. This included, facilitated patient empowerment, patient education and psychological support. One participant in this study stated that “Having a trusted person and being able to tell him when you feel sick, receiving the physician’s trust and help is very important” (p. 9). Each of these aspects are discussed further in the next sections.

The Osteopathic Council NZ, (2014), supports the idea of patient-centred care in their Code of Ethics, stating that osteopaths are encouraged to provide patient-centred care by ensuring that patients feel “informed, acknowledged, respected, valued and safe”.

**Empowerment**

Empowerment is a concept that was introduced in the 1970s and 1980s, by the self-help movement and has continued to grow since (Kieffer, 1984). The concept was originally developed by Brazilian educator Paulo Freire and aimed to increase the autonomy, power and influence of oppressed groups (Kieffer, 1984). Freire viewed empowerment as both a process and an outcome, using education as a process to increase one's ability to act autonomously and enhance a sense of self-efficacy.

Patient empowerment has become a high priority for healthcare policy makers internationally. Shared decision making has been considered by participants to be an empowering experience (Schulz & Nakamoto, 2013). Patient empowerment tends to be considered broader than patient-centred care and can place greater demands on healthcare professionals (Holmström & Röing, 2010). The World Health Organisation defines empowerment as “a process through which people gain greater control over decisions and actions affecting their health” (World Health Organisation, 1998, p. 14). Empowerment in healthcare encourages patients to be an active participant in the
decision-making process about their health and quality of life (Kieffer, 1984). By increasing the role of patients, health care providers become more responsive to patients' needs and preferences and deliver better quality care.

Angelmar and Berman (2007), describe four components that are regarded as integral for patient empowerment; patient knowledge of his/her role during management; sufficient knowledge for effective communication between healthcare provider and patient; patient skills; and an environment that supports empowerment. Furthermore, a randomized control trial performed by Altshuler et al., (2016) demonstrated how the empowerment of diabetic patients within the medical encounter improved health outcomes.

Literature shows that a patient-centred approach is seen as a prerequisite for the empowerment process (Holmström & Röing, 2010; Anderson & Funnell, 2010; Piper, 2010). It is now being recognised that both the patient and professional’s knowledge is important for the success of the treatment and improving the quality of care (Coulter & Ellins, 2007; Loder, Bunt & Wyatt, 2013; Embuldeniya et al., 2013). Patients are starting to be acknowledged as experts regarding their own bodies, symptoms and situations and through the process of empowerment patients appear to develop an inner strength (Aujoulat, Marcolongo, Bonadiman & Deccache, 2008; McAllister, Dunn, Payne, Davies & Todd, 2012) and gain more cognitive, decisional and behavioural control over their lives (Aujoulat, d’Hoore & Deccache, 2007; McAllister et al., 2012). Such control is further supported through patient education. This is important as a reduced sense of control is strongly associated with psychiatric conditions such as depression and anxiety (Keeton, Perry-Jenkins & Sayer, 2008), which have been managed through the use of CAM (Pilkington, 2018), and are the most common disorders associated with endometriosis (Laganà et al., 2017).

**Education**

Progress in the understanding of pain has led to a fundamental shift in management approaches. Self-management programs incorporate the physical, psychological, and social dimensions (Reid, Eccleston & Pillemer, 2015). Pain biology education which emerged about 15 years ago (Moseley & Butler, 2015) is now recognized as an important part of pain management (Maher, Underwood & Buchbinder, 2017). Pain education aims to give patients an overview of the underlying physiological
mechanisms and adaptive processes which support persistent pain, such that pain becomes ‘over-protective’ (Moseley & Vlaeyen, 2015; Lee et al., 2015). Patients are taught strategies to manage pain by altering their behavioural, cognitive, and emotional responses to pain and developing self-efficacy (Reid, Eccleston & Pillemer, 2015).

Moseley, (2004), demonstrated that changes in pain cognitions is associated with change in physical performance, even without physical activity. Using a multiple regression analysis of 121 patients with chronic lower back pain, the researcher evaluated the relationship between change in pain cognitions by the Survey of Pain Attitudes questionnaire (SOPA) and the Pain Catastrophising Scale (PCS) and any changes in physical performance, measured through performing a straight leg raise (SLR) and standing forward bending range. Results revealed that there was a strong relationship between changes in cognitions (change in the conviction that pain relates to tissue damage and catastrophising ) and changes in the physical performance of SLR and forward bending ($r = 0.88$ and $0.79$, respectively, $p < 0.01$). This research demonstrated how our cognitive understanding of pain and how we emotionally respond to pain can positively affect physical performance.

A similar study by Moseley, Nicholas and Hodges, (2004) used a randomized controlled trial, to measure the effect that education about pain neurophysiology could have on pain cognitions and physical performance on 54 participants with chronic lower back pain. Individual education sessions on neurophysiology of pain education show a significant improvement on the SOPA ($p < 0.001$), PCS ($p < 0.001$), SLR ($p < 0.01$), and forward bending ($p < 0.01$). However, there was no effect on the perception that pain is necessarily associated with disability ($p = 0.31$). This study contributes to the growing body of research demonstrating that education about pain neurophysiology can have a positive effect on not only pain cognitions, but also physical performance.

More recently, an interpretative phenomenological study by Robinson, King, Ryan and Martin, (2016), used semi-structured interviews to collect data on ten adults with chronic musculoskeletal pain. Participants were interviewed two weeks prior to completing a two hour pain neurophysiology education. Eight out of ten participants found the education relevant and reported benefits ranging from a better
understanding of pain, improved ability to cope with the pain, and some suggested improved levels of physical activity, while two participants reported no benefit and did not perceive the material to be relevant to themselves.

A much larger study by Mittinty, Vanlint, Stocks, Mittinty and Moseley, (2018), had similar results to the previous studies mentioned. They collected data from 573 participants who were using supplementation (control group) or pain education (intervention group) as management for CP. Findings from this patient-reported internet survey suggested that pain education induced positive change in pain cognition (unadjusted OR = 2.06; 95% CI = 1.34–3.16) and self-management of pain (unadjusted OR = 2.06; 95% CI, 1.34–3.16), which in turn, influenced reported pain intensity and recovery in CP patients.

**Psychological Support and trust**

Trust is an important component in CP management and the clinician–patient relationship (Buchman, Ho & Illes, 2016). It is also central to the patient–practitioner relationship (Pearson & Raeke, 2000; Phillips-Salimi, Haase & Kookan, 2012) and patient centred care (Sakallaris, Miller, Saper, Jo Kreitzer & Jonas, 2016). Trust is an essential component to a successful treatment outcome (Calnan & Rowe, 2006; Croker et al., 2013; Birkhäuser et al., 2017) as it ensures patient adherence to treatment and effective practitioner-patient communication, which has shown to be fundamental to a successful treatment outcome (Hall, Dugan, Zheng & Mishra, 2001; Calnan & Rowe, 2007).

Gilson, (2003) explains, to trust someone is a “voluntary action based on expectations of how others will behave in relation to yourself in the future” (p. 1454). For example, when there is trust between a patient and clinician, both parties believe that they will and are acting honestly and in each other’s best interest (Hall, Dugan, Zheng & Mishra, 2001). With this in mind, when a patient has had negative experience with clinicians or the healthcare system previously, they may be suspicious about the clinician’s intentions (Govier, 1997; Matthias et al., 2013), which in turn can affect the patient-practitioner relationship.
The association between trust and health outcome tends to differ between individual studies. For example, a study by Lee and Lin, (2011) looked at a sample of patients diagnosed with diabetes. The results of this study highlighted that trust in the clinician was positively related to both objective and subjective health outcomes including HRQoL and patient satisfaction. However, in contrast, a study by Abel and Efird, (2013) reported that for patients with hypertension, there were no significant correlation between trust and subjective outcomes such as blood pressure control.

Previous research has looked at trust and patient-practitioner relationship and how this could influence patient health outcomes, Lee and Lin, (2008) explain that a patient’s experience is a critical factor that influences the level of trust and propose that patients’ trust can influence health outcomes through patient disclosure, placebo, compliance, and the physicians caring behaviour.

A later study by Lee and Lin, (2010) explores the theoretical and empirical relationships between 614 patients perceptions of autonomy support and preferences in regard to their health outcomes. Self-rated health status among patients was operationalized using SF-12, while patient satisfaction was measured using the Patient Visit Specific Questionnaire. In this study, the main finding is that patients who perceived greater autonomy support had higher trust and satisfaction ratings regarding their physicians (p < .05). Patients with high decisional preference experienced a greater increase in subsequent trust and satisfaction.

An interesting qualitative study by Tarrant, Dixon-Woods, Colman and Stokes, (2010), used semi-structured interviews to explore 20 patients accounts of trust in general practitioners (GP) in the UK. In this study participants described the trust during one consultation was developed through the GP’s behaviour, showing competence and actions with regards to the patients best interest. Many patients preferred to see trust as an integral part of an ongoing relationship with a GP. With repeated positive interactions, ongoing trust was maintained and reinforced when patients perceived that the care they received was appropriate and effective, or if GPs demonstrated awareness of their limited expertise. This contributed to confidence and security felt by the participants towards the GP. These findings suggest that trust is not developed only through repeated interactions, but rather trust is dependent on what happens during consultations and the characteristics of the GP.
Trust can behave and change multiple times over the course of a relationship. It can build strength or rapidly deteriorate through expectations and changes in experience (Hall, Dugan, Zheng & Mishra, 2001). However, patients who do report higher trust in their healthcare professional and satisfaction with treatment, tend to display more positive health behaviours, less symptoms and higher quality of life. Also, a lack of trust in mainstream health has been shown that patients are more inclined to use CAM (Suarez & Reese, 2000; Cauffield, 2000; Hall, 2001).

**Overview of Complementary and Alternative Medicine**

Complementary and alternative medicine is defined as a varied group of medical and healthcare systems, practices and products that are not considered part of conventional medicine (Tabish, 2008). Sinaii et al. (2007) reported the most commonly used alternative treatments for the management of endometriosis were biologically based therapies and manipulative and body-based therapies.

Although there is little scientific evidence available regarding the use of CAM for the management of endometriosis (ESHRE Endometriosis Guideline Development Group, 2013), the use of CAM as a general healthcare option has increased worldwide in recent years (Frass et al., 2012; Schwartz et al., 2019). Rationale for this increase has been associated with dissatisfaction with orthodox medicine, the perceived naturalness of CAM, the rapport built with CAM practitioners and the individualised interventions that are recommended, thus increasing the control an individual has over their healthcare (Rayner, McLachlan, Forster & Cramer, 2009). Patients report different reasons for using CAM including dissatisfaction with conventional medicine, a sense of recognition and gaining a more active role in treatment and with that a sense of control (Van Den Brink-Muinen & Rijken, 2006).

Studies have reported that CAM, including the use of supplements and manual therapy, had been used by 84% of women for musculoskeletal pain management in the previous 12 months and 87% of those patients indicated that they would use CAM again due to the lack of side effects (Fisher et al., 2004; Rubinstein et al., 2010). It is becoming common for support groups and forums to provide articles and encourage the use of physical therapy, nutrition/diet, acupuncture, homeopathy, and other
potential treatments that alleviate symptoms (Endometriosis New Zealand, 2017; Endometriosis New Zealand, 2017).

**Complementary and alternative medicine for management of endometriosis and chronic pain**

There appears to be a role for CAM therapy in the treatment of CP syndromes (Thomas et al., 2016) such as endometriosis. As our understanding of the biological and neurophysiological component of CP has increased, treatment has shifted from more traditional treatments of medication to a biopsychosocial approach including the biological, psychological, and social components (Turk, Swanson & Tunks, 2008).

CAM therapies such as physical therapy, and both behavioural and cognitive techniques have shown to reduce pain and improve QoL in women with endometriosis (Awad, Ahmed, Yousef & Abbas, 2017; Bergstrom, Freyschuss, Jacobsson & Landgren, 2005; Wurn, Wurn, Patterson, Richard King & Scharf, 2011). This is done by using exercise therapy (Hayden, Van Tulder, Malmivaara & Koes, 2005), manual techniques such as myofascial release (Wurn et al., 2011) and behavioural techniques to encourage relaxation of the body and mind (Friggi Sebe Petrelluzzi et al., 2012). Techniques such as manual manipulation and myofascial release that are used in therapies such as acupuncture, chiropractic and massage are also incorporated into osteopathy will be discussed in further detail in the following chapters.

**Acupuncture**

Techniques such as acupuncture base their treatments on the idea of inducing physiological and psychological changes, such as activating the endogenous descending pain inhibitory systems, deactivating areas of the brain that transmit sensations of pain and changing the interaction between nociceptive impulses and somato-visceral reflexes (Lund & Lundeberg, 2016). There is little reliable research exploring the effects of acupuncture on the symptoms of endometriosis and even fewer randomised, blinded clinical trials. The studies that are available have small sample sizes and lack validity.
A prospective, randomized, sham-controlled trial by Wayne et al., (2008) is one of the only randomised controlled trials that select sham acupuncture as the control intervention. They followed eighteen young women (13-22 years) who underwent a total of 16 acupuncture treatments; 2 per week for 8 consecutive weeks. All outcome measures were assessed at baseline, then at 4 weeks, 8 weeks, and finally 6 months after the commencement of acupuncture treatment. Outcomes were assessed using the Endometriosis Symptom Severity Scale, EHP-30, The Pediatric Quality of Life Inventory, The Perceived Stress Scale and a participant generated list of 3 activities made difficult due to pelvic pain. Participants in the active acupuncture group experienced a mean 4.8-point (SD = 2.4-point) reduction of pain (62%) after 4 weeks (p = 0.004) compared to the control. The reduction in pain in the active group persisted through a 6-month assessment. All HRQoL measures indicated greater improvements in the active acupuncture group compared to the control; however, the majority of these trends were not statistically significant.

A study with low bias by Xiang, Sun and Liang, (2011), looked at the effect abdominal acupuncture has on pain relieving in pelvic cavity in patients with endometriosis when compared to Chinese medicine. Fifty-eight participants were randomly divided into 2 groups. Abdominal acupuncture points were adopted for the abdominal acupuncture group, while the Chinese medicine, Tianqi Tongjing capsule for dysmenorrhea was taken by the Chinese medicine group. Outcomes were measured both before and after the interventions using the McGill pain questionnaire, and by measuring the level of serum CA125. This was used because concentrations of CA125 are markers for the diagnosis of endometriotic disease in patients with CPP (Oliveira, Raymundo, Soares, Pereira & Demôro, 2017). The McGill questionnaire demonstrated that both groups pain had improved after treatment (p = 0.01). However, the level of CA125 had reduced further for the acupuncture group (p < 0.01) than for the traditional Chinese medicine group (p = 0.05). From this study it appears that acupuncture appears to be effective in reducing pain and serum CA-125 levels in endometriosis. However, it should be acknowledged that the effects of expectation or other non-specific factors may have contributed to the benefits seen in the present study.
**Massage**

Massage therapy treatment is based on the idea that mobilisation of soft tissue may break collagenous cross-links and adhesions that are associated with dysfunction and pain (Threlkeld, 1992). Wurn et al., (2004a), explain that, theoretically, by restoring visceral, osseous, and soft-tissue mobility, the use of massage therapy on soft tissue of the abdomen and pelvic cavity may reduce uterine spasms and cervix adhesion, and therefore reduce pelvic pain and assist in fertility for women with particular dysfunctions surrounding their pelvic organs.

A prospective analysis on 18 patients diagnosed with endometriosis, used a 10-point pain scale on which they rated their average pain during ovulation, pre-menstruation, menstruation, and sexual intercourse pre and post treatment. This procedure showed a significant decrease (p = 0.001) of pelvic pain, close to menstruation and ovulation, in response to massage therapy (Wurn et al., 2006).

A semi-empirical clinical trial by Valiani, Ghasemi, Bahadoran and Heshmat, (2010), 23 patients diagnosed with and suffering from endometriosis. The visual analogue scale (VAS) was used to and McGill questionnaire were used to measure the severity of pain. These were measured once before and twice after the end of intervention for each patient (immediately post intervention and six weeks after that). There was a statistically significant difference between the intensity of pain before the intervention started, immediately after, and six weeks following the intervention (p < 0.001).

The results of some articles suggest that massage therapy could be effective for management of endometriosis (Wurn et al., 2004a; Wurn et al., 2006; Wurn et al., 2004b). However, the research is limited and without sufficient methodological detail of the studies to ensure reliability and validity. Further, not all relate massage therapy directly with symptoms associated with endometriosis. More research however has examined how massage therapy can help indirectly, for example with symptoms associated with endometriosis such as lower back pain (Field, 2016; Elder et al., 2017) and pelvic pain (Field, 2016).

Elder et al., (2017) performed a measured cohort study. In this study primary care providers referred eligible patients for 10 massage sessions. Measurements were obtained at baseline and then at 12 and 24 weeks post-intervention through the
Oswestry Disability Index and SF-36v2. Group means improved at 12 weeks for all outcomes and at 24 weeks for SF-36v2’s Physical Component Summary and Bodily Pain Domain. Of those with clinically improved disability at 12 weeks, 75% were still clinically improved at 24 weeks (p < 0.01). For SF-36 v2 Physical and Mental Component Summaries, 55.4% and 43.4%, respectively, showed clinically meaningful improvement at 12 weeks, 46.1% and 30.3% at 24 weeks. For Bodily Pain Domain, 49.4% were clinically improved at 12 weeks, 40% at 24 weeks.

A randomized controlled trial by Azima, Bakhshayesh, Kaviani, Abbasnia and Sayadi, (2015) on pelvic pain in 102 participants, compared massage (n=32) to isometric exercises (n=24) for the treatment of pelvic pain associated with primary dysmenorrhea. The disparity between the number of participants was due to participant dropout. The treatment lasted eight weeks and the two groups were compared to a no-treatment control group. Pain intensity was measured and recorded by using a VAS while the duration of pain was measured in hours, anxiety levels were measured using the Spielberger's questionnaire. Pain intensity was significantly reduced in both treatment groups, however, the reduction was greater in the massage group (p < .001). While intragroup comparisons showed a significant reduction of anxiety level in the massage group only after the third cycle (p = 0.017).

These results suggest that massage could be beneficial for women suffering from pain symptoms associated with endometriosis. However, most studies measured menstrual pain without a diagnosis of the stage of endometriosis which means that it is more difficult to transfer the results to general population.

**Chiropractic**

Chiropractic care focuses on the body’s structure in relation to its function. Chiropractors tend to use manual spinal manipulation to, theoretically, encourage proper alignment of the body's musculoskeletal structure, and to help the body heal itself (Harvard Health, 2018).

Very few studies have been performed on the use of chiropractic care for the treatment of endometriosis-related symptoms and results thus far have been inconclusive. Similar to other CAM therapies there are studies that suggest that
chiropractic care could help alleviate or relieve pains including lower back pain and pelvic pain (Spears, 2005; Holtzman, Petrocco-Napuli & Burke, 2008), and also have a positive effect on infertility (Kaminski, 2003).

Hawk, Long and Azad, (1997) performed a prospective single-group intervention study to assess the role of chiropractic care for eighteen women with CPP, using techniques consisting of flexion/distraction and trigger point over a period of six weeks. Outcome measurements were administered at baseline and at six weeks, using the Pain Disability Index (PDI), the VAS for pain, and the Health Survey and Beck Depression Inventory (BDI). The mean improvement in the PDI score was 13.0 points (p = 0.001); in the VAS it was 4.0 cm (p = .001); and in the BDI it was 6.1 points (p < 0.001). The treatment in this study appeared to have positive short-term effects and supports further study to examine the outcome on multiple participants.

Therapies such as chiropractic that include spinal manipulation and mobilization, are often used successfully together as well as alone to treat chronic non-specific low back pain (Santaguida et al., 2009; Furlan et al., 2010; Coulter et al., 2018) which is a common symptom of endometriosis. The efficacy of manipulation and mobilization may vary depending on the duration of symptoms, how the intervention is administered and the character of the therapist (Coulter et al., 2018). Osteopathy and chiropractic come from similar origins and both work with the musculoskeletal system, using palpation to diagnose and treat abnormalities of both structure and function (Vickers & Zollman, 1999). Therefore, these results can easily be transferred to the effects that an osteopathic care could have on patients with non-specific lower back pain and symptoms of endometriosis.

**Overview of osteopathy**

In this section the philosophies and treatment concepts of osteopathy will be discussed and literature surrounding the experience of osteopathic care. Finally, the available research surrounding osteopathic care and endometriosis will be discussed and critiqued.
The philosophy and treatment concept of osteopathy

Originally the term “osteopathy” was described by Andrew Taylor Still as a diagnosis and treatment based on musculo-fascial structures and their influence on somatic signs and symptoms (Sillem et al., 2016). Osteopaths utilise manual contact for both diagnosis and treatment and consider the relationship of body, mind and spirit in both health and disease (World Health Organisation, 2010). The practice of osteopathy is guided by four principles that define its philosophy and guide clinical decision-making. These are; the body is a unit; the body possesses self-regulatory mechanisms; structure and function are reciprocally interrelated; and rational therapy is based upon these principals. Although originally considered radical, these principles are now promoted within most healthcare professions with a patient-centred care approach (Tyreman, 2013).

In NZ, osteopathy is considered part of CAM, and, until recently, osteopathic techniques had not been extensively researched (Schneider-Milo, 2011). Many osteopathic treatments and techniques are based on traditional knowledge of anatomy and physiology. The goal of osteopathy is utilising this understanding and incorporating the factors required to manage a patient’s unique response to pain in a drug and surgery-free approach (Kuchera, 2007).

Osteopathic manual treatment has been shown to substantially reduce pain in patients with chronic lower back pain by providing important improvement in back-specific functioning and has been recommended as an option for patients before proceeding with more invasive and costly treatments (Licciardone, Kearns & Minotti, 2013).

The osteopathic experience

The importance of identifying expectations and their effects on patient satisfaction and experience has been demonstrated in numerous studies (Gerteis & Picker/Commonwealth Program for Patient-Centered Care, 1993; Potter, Gordon & Hamer, 2003; Rao, Weinberger & Kroenke, 2000; Verbeek, Sengers, Riemens & Haafkens, 2004). Strutt, Shaw and Leach (2008) have performed one of the few studies which included investigating the patient perspectives on the osteopathic care
and treatment outcomes. Their study revealed that in primary healthcare, patient satisfaction is associated with becoming empowered, gaining control of one's life and achieving an empathetic therapeutic relationship. The development of a successful therapeutic relationship was associated with hope, communication, respect, and trust. This study highlighted important issues around respect such as undressing, privacy and gender which were concluded to be a large barrier to attendance (Strutt, Shaw & Leach, 2008). A study performed by Thomson and Collyer (2017), demonstrated that the language used by an osteopath can contribute to the patient beliefs and enhance patient engagement. The authors highlighted how participants can have a range of interpretations in response to the language used by student osteopaths when discussing pain. The use of medical words, metaphors and analogies, reassurance and the patient-practitioner relationship were all factors which could influence participants’ engagement and taking an active role in their care.

**Osteopathy for Management of Endometriosis**

Tettambel (2005) suggests that osteopathic physicians should be well trained to contribute to the management of symptoms such as CPP through addressing biomechanical structures and somatic dysfunction that could be contributing to CPP. Management of CPP requires a multidisciplinary approach (Magistro et al., 2016). With this in mind, osteopaths should be well prepared to contribute to the management of CPP in women by acknowledging the emotional, psychological, and structural aspects of the condition (Engeler et al., 2013). There are studies that suggest osteopathy provides effective management for many types of pain (Aveni, Berna & Rodondi, 2017; Cerritelli, Lacorte, Ruffini & Vanacore, 2017; Gesslbauer, Vavti, Keilani, Mickel & Crevenna, 2018; Switters, Podar, Perraton & Machotka, 2019). While the sample sizes of these studies are small, they show a trend towards a positive influence that osteopathic management has on pain and QoL.

Hogg and Vyas (2018) explain that there is a significant amount of research that exists surrounding the topic of endometriosis, with a 21.5% increase in the total number of scientific papers on the topic published since 2008. While there is anecdotal evidence that women with endometriosis seek osteopathic care, there is a lack of current qualitative research regarding patient experience of osteopathy as a treatment or management for endometriosis. There are five different quantitative
research articles associated with endometriosis (Daraï et al., 2015; Goyal et al., 2016; Ruffini et al., 2016; Schneider-Milo, 2011; Sillem et al., 2016) and no qualitative research. Three out of the five studies utilised questionnaires to measure treatment outcomes associated with QoL and endometriosis-related pain. Three research articles specifically assessed osteopathic techniques for symptoms in women diagnosed with endometriosis, while the other two assessed other gynaecology and obstetrics associated symptoms not necessarily related to endometriosis. The three research articles related directly to endometriosis included, one Master thesis and two pilot studies.

The Master thesis by Schneider-Milo (2011) used a non-randomized, non-blinded design, to assess the effectiveness of osteopathy as a complementary treatment for 20 women with endometriosis-related pain. Intervention included a complete full-body check-up with a specific focus on the pelvis. Osteopathic techniques were then applied and included joint manipulation, muscle energy technique and general osteopathic technique. Each unique treatment was tailored to the examination findings. In total, the patients received four treatments and rated their pain each month. The results revealed a significant decrease of perceived pelvic pain ($p = 0.007$) and an improvement in some domains of health-related quality of life (QoL) in relation to pain, sense of control, social support, work and treatment. Similarly, an improvement in QoL measures was found for 20 women living with Deep Infiltrating Endometriosis (DIE) with colorectal involvement (Daraï et al., 2015).

Daraï et al., (2015), performed a prospective pilot study on 20 participants aged between 22 and 39 years of age diagnosed with DIE and colorectal infiltration. To measure the potential role of osteopathic manipulative therapy (OMT) on QOL, the SF-36, QOL questionnaire was utilised and participants reported before and after undergoing OMT. As there was no data on the OMT for DIE, treatment was based on OMT previously recommended in the treatment of dysmenorrhea. Treatment included mobilization of the uterus and colon, and an indirect technique and manual manipulation to the lumbar spine. This treatment appeared to be more structured than the study by Schneider-Milo (2011), as the same techniques were applied to each participant but varied in direction and magnitude of movement. In this study, there were no differences in the epidemiological characteristics or in the pre-OMT Physical Component Summary and Mental Component Summary of the SF-36 questionnaire.
between patients who completed the protocol or not. After a mean period of 24 days (15–53), a significant improvement in PCS (p = 0.03) and MCS (p = 0.0009) compared to pre-OMT values was observed giving a success rate of 80% and 60% in intention-to-treat. These results show some evidence as to why anecdotally women seek osteopathic care for management of endometriosis as OMT appears to be associated with short-term improvement in QOL of patients.

Recently, Sillem et al. (2016) performed a pilot study that investigated 28 patients from a certified endometriosis centre with the primary complaint of chronic lower abdominal symptoms and a clinical finding of painful pelvic floor muscle tightness. In this study, treatment depended on clinical findings, and included techniques similar to the ones performed by Daraï et al., (2015), including mobilisation of the diaphragm and abdominal organs, while the “grand manoeuvre”, which is a direct technique, was used to release the pelvic floor. These techniques were also well received by women with painful pelvic floor muscle tightness, with 10 of the 14 patients diagnosed with endometriosis reporting improvement in pelvic pain and tension. Research suggests that physiological correlations exist between pelvic floor dysfunction and pelvic pain (Yehuda Rosenbaum, 2007).

CP associated with endometriosis is the main symptom that affects QoL negatively (Bloski & Pierson, 2008; Jones, Jenkinson & Kennedy, 2004). Therefore, it is not surprising that techniques targeted at the pelvic floor can have an effect on pain levels and QoL for women living with endometriosis.

Goyal et al. (2017) produced a case report to explore the effect of osteopathic treatment for women with abnormal uterine bleeding-related pain and the impact on their health-related QoL. This case report followed a 29-year-old female diagnosed with endometriosis through ultrasound. The osteopathic treatment plan consisted of 2 sessions per week for 4 weeks. Results demonstrated a positive influence on symptoms such as the abnormal uterine bleeding related pain and HRQoL when an osteopathic manipulative approach was utilised.

A review evaluating the evidence of OMT on gynaecologic and obstetric conditions concluded that although positive effects were found for some conditions, the heterogeneity of study designs, the low number of studies and the high risk of bias
prevented any generalisation on the effect of osteopathic care on gynaecologic and obstetric conditions (Ruffini, D’alessandro, Cardinali, Frondaroli & Cerritelli, 2016). There is not enough research to conclusively recommend OMT for every woman diagnosed with endometriosis. The equivocal research may illustrate that osteopathic treatment success is individual and based on a number of factors including patient compliance, patient belief, regularity and techniques of the treatment, as with any other manual therapy.

Summary

This literature review explored the subjective experience of endometriosis and what is known on current management for symptoms associated with the condition. A discussion occurred on important aspects of the clinical encounter, and different natural therapies that could potentially play a role in the management of endometriosis.

At present many women are experiencing symptoms of endometriosis in NZ which have a direct impact on their QoL through pelvic pain and infertility, loss of income and healthcare costs (Klein et al., 2014; Moradi et al., 2014). A patient’s response to interventions, and the severity of pain experienced by the patient contribute to the reduction of QoL in patients with endometriosis. The CP component of endometriosis is complex in nature, involving an unpleasant sensory and emotional experience not necessarily associated with tissue damage. Management of these symptoms should be interdisciplinary and multidisciplinary and ensure that the care is patient-centred. With this in mind, literature demonstrates how manual therapies such as osteopathy may have an important role in the management of endometriosis. Research on how osteopathic care benefits individuals with endometriosis is severely limited. In the research available, sample sizes were so small that it is difficult to apply the results generally. This literature provides support for further research, particularly randomised controlled trials assessing techniques to the abdomen and pelvic floor. It appears from the literature that both direct and indirect techniques commonly used in osteopathic treatment can provide some relief from symptoms commonly found associated with endometriosis. However, there is a severe lack of research exploring the patients experience of osteopathic care, and therefore it is not known what
component of the clinical encounter patients consider the most beneficial, particularly taking into consideration the psychosocial burden of endometriosis.

This study hopes to address this gap by exploring women’s experiences of osteopathic care whilst living with endometriosis. Additional knowledge may be gained to provide insights for practitioners regarding how to improve their treatment and ways of supporting women as they manage this highly complex condition. It also seeks to establish a case for further research into osteopathy as supplementary management for conditions such as endometriosis.
CHAPTER FOUR - METHODOLOGY AND METHODS

Introduction

This chapter explores the theoretical aspects of the selected research methodology. It provides an examination of qualitative research methodologies and then progresses to discuss qualitative description as a research approach and philosophy. This discussion is followed by a review of the data gathering and analysis method used in this study and an examination of rigour in the context of qualitative research. The application of the theoretical aspects to this study will be discussed later within the chapter.

Qualitative Research Methodologies

This study into women’s experiences of osteopathic care whilst living with endometriosis uses a qualitative descriptive approach. As little research on the use of osteopathy for the management of endometriosis had been published, an exploratory study was seen as the most useful approach (Van Manen, 1990). Exploratory studies can provide vital information for the evaluation of complex public health interventions (Hallingberg et al., 2018). A qualitative approach was selected as it has the capacity to explore substantive areas about which there is little knowledge (Strauss & Corbin, 2008), such as this project exploring the osteopathic care and treatment experience of women with endometriosis.

Qualitative research is a form of social inquiry that explores the way people make sense of their experiences and the world they live in (Holloway & Galvin, 2017). It can include intricate details such as feelings, thought processes and emotions which are often difficult to extract or learn about through quantitative research methods (Strauss & Corbin, 2008). Qualitative research is increasingly being used in healthcare research exploring social and cultural dimensions (Al-Busaidi, 2008). This is because it can assist in the development of concepts that can help understand the chosen phenomena in natural settings, while understanding the participants’ meanings, experiences and views through observations and/or interviews (Mays & Pope, 1995). Qualitative research methods can enable health researchers to examine
healthcare practices and processes, highlight barriers and facilitators to change, and discover the reasons for the success or failure of interventions (Starks & Trinidad, 2007).

**Qualitative Descriptive Research**

Qualitative research uses multiple approaches that are interactive and humanistic (Creswell, 2003). Some of these methods include interpretive description, qualitative description, hermeneutic phenomenology, grounded theory and narrative approach. Of these approaches, qualitative description was selected as the most suitable approach to answer the research question for this study.

Qualitative description is a distinct method of naturalistic inquiry research that seeks to discover and understand a particular experience, through low inference interpretation to present the perspective and worldviews of the people involved (Caelli, Ray & Mill, 2003; Merriam, 1998; Sandelowski, 2000). Qualitative description studies provide a summary of insights from an individual’s experience in the area that is so far poorly studied.

Polit and Beck, (2014) reported that qualitative descriptive studies accounted for more than half of published qualitative studies. These studies are typically used to discover the who, what, where, and why of events or experiences (Neergaard, Olesen, Andersen & Sondergaard, 2009) and are often used in nursing and midwifery research, as they explore meaning and how people make sense of the world to provide direct descriptions of their experience and promote person-centred care (Sandelowski, 2000; Bradshaw, Atkinson & Doody, 2017).

Qualitative description aims to understand an event or experience through gaining the meanings participants describe to them. The naturalistic aspect of this methodology is relativism, which is subjective and varies from person to person (Parahoo, 2014). No description is free of interpretation and descriptions are influenced by the perceptions and biases of the person describing them. Researchers naturally highlight certain aspects of the experience that they deem ‘important’ and with that begin to transform that experience or event (Sandelowski, 2000). However, qualitative description (as opposed to phenomenological or grounded theory description), entails a kind of
interpretation that is likely to result in consensus among researchers, because it interprets the findings without moving far from that literal description. This means that researchers using qualitative descriptive stay closer to raw data during the analytical process and presentation of results (Neergaard et al., 2009).

Maxwell, (1992) explains that descriptions must accurately convey experienced events in their correct sequence and maintain the validity and meaning that individual participants attribute to those events. Through a rich description from the participants’ subjective experience, qualitative description offers a rare opportunity to gather rich details about a phenomenon which little may be known about (Bradshaw, Atkinson & Doody, 2017).

Unlike traditional qualitative methodologies, which are built upon philosophical and methodologic frameworks from distinctive disciplinary traditions, qualitative description tends to draw from the general principles of naturalistic inquiry and thus to study something in its natural state within the context of the research topic. This means there is no prior biases to any one theoretical view of a specific phenomenon (Colorafi & Evans, 2016) and minimal pre-existing ‘theoretical’ or philosophical restrictions (Lambert & Lambert, 2013). However, they may have some of the overtones of the other approaches (Lambert & Lambert, 2013).

Qualitative description research seeks to provide a rich description of the experience depicted in easily understood language (Sullivan-Bolyai, Bova & Harper, 2005). The knowledge gained from qualitative description is often used to influence interventions (Sullivan-Bolyai et al., 2005) and can often be of special relevance to practitioners and policy makers (Sandelowski, 2000). Therefore, a fundamental qualitative description design in research is valuable in its own right.

In this study, it was appropriate to use a qualitative descriptive methodology as it allows the researcher to seek, discover and understand women’s experiences of using osteopathy as a CAM treatment for their endometriosis from their perspectives and worldviews.

This is an important first step in this research area as there is currently little known about patient experiences of osteopathic care when managing endometriosis and other
genealogical conditions and will provide insights for practitioners as to how to improve the treatment for women as they manage endometriosis and will help provide a precursor to future research.

**Qualitative Data Collection**

In qualitative description studies, data collection focuses on discovering the nature of the specific events under study (Lambert & Lambert, 2013). Data collection methods can include but are not limited to, minimal to moderate, structured and open-ended, individual or focus group styled interviews, observation, or document review (Lambert & Lambert, 2013; Colorafi & Evans, 2016). Qualitative interviews are a prominent method of data collection in social sciences depending on the research question being asked (King, Horrocks & Brooks, 2018). Qualitative interviews vary in methodological features such as length, style of questioning, and participant numbers. For this research, in-depth, semi-structured, face-to-face interviews were considered the best method to collect descriptive data on women’s experiences of osteopathic care while living with endometriosis. Semi-structured interviews are considered in-depth as the participant answers open-ended questions (Jamshed, 2014) and therefore do not have pre-determined answers, allowing participants to respond in their own terms (Berry, 1999).

A semi-structured format of interview is used most frequently in healthcare. The flexibility of this approach allows for the discovery or elaboration of information which may be important to participants but may not have initially been thought of as relevant by the researcher (Gill, Stewart, Treasure & Chadwick, 2008). Unlike a structured style interview, such as a questionnaire, a semi-structured interview format is only relatively set. This method of interview is used when researchers have a broad set of questions that need to be addressed surrounding the participants subjective experience which is then supplemented by follow up questions and probes (Polit & Beck, 2010; DeJonckheere & Vaughn, 2019). An interview guide is used, however, the interviewer has the freedom to be led by the participants thoughts and further explore tangential ideas that may arise (Bell, 2014).
In-depth interviews are used to understand the experience of other people and what that means to them (Seidman, 2006). With this in mind, interviewers are required to have an inquisitive mind and a focus on the participant and what they have to say.

The face-to-face nature of the interview potentially allows the interviewer to gather a greater amount of information as social cues, such as voice, intonation, body language can be accounted for (Opdenakker, 2006). Nonverbal communication such as hand gestures is an important source of information throughout the interview process as it can convey expressive information that may be critical to communication (Denham & Onwuegbuzie, 2013). Therefore, a journal of field notes (Appendix A), was kept and used soon after the completion of each interview as a means of documenting needed contextual information.

**Rigour in Qualitative Research**

Much like quantitative research, the main strategy to ensure rigour in qualitative research is systematic and conscious research design, data collection, interpretation and communication (Mays & Pope, 1995). Rigour of qualitative research relies on reliability and validity which are both necessary components of quality (Brink, 1993; Tappen, 2011). Researchers should aim to create an account of method and data which stands independently and could easily be replicated by another trained researcher, resulting in the same conclusion (Ryan-Nicholls & Will, 2009). Morse (1991) explained that validity can be achieved by using the method of open-ended, unstructured interviews with strategically chosen participants. Additionally, validity can be supported by using logical and recognised systems of reporting (Ryan-Nicholls & Will, 2009), such as the NVivo tool used in this project. These methodological strategies are applied to ensure the ‘trustworthiness’ of the results.

There are several definitions and criteria of trustworthiness, however, the best-known principles are credibility, transferability, dependability and confirmability as defined by Lincoln and Guba (1985). These principals are an important framework for all qualitative researchers and can be easily applied to qualitative description research. This section explores how these principles have been addressed throughout this research.
**Credibility**

Credibility in qualitative research refers to the confidence that can be placed in the internal validity of the research findings (Holloway & Wheeler, 2002; Macnee & McCabe, 2008). This is important as credibility establishes whether the research findings represent reasonable information drawn from the participants original data and is an accurate interpretation of the participants original views (Lincoln & Guba, 1985). Credibility was established through various methods throughout this research process including face-to-face observation during interviews, field journals, triangulation, audit trails, peer examination and established interview techniques (Anney, 2014; Cope, 2014).

Validity during data generation was achieved by documenting data collection decisions, ensuring verbatim transcription was used and continuing until data saturation was achieved (Sandelowski, 1993). Saturation was recognised by both the researcher and her supervisor when there was enough information for the study to be replicated (O’Reilly & Parker, 2012; Walker, 2012), when there was no new information attained throughout individual interviews and during the interview process (Guest et al., 2006), when further coding is unnecessary (Guest et al., 2006) and the depth of the data was satisfactory (Burmeister & Aitken, 2012).

Data triangulation can be a significant method for achieving data saturation and enhancing the reliability of results (Stavros & Westberg, 2009). Triangulation is a way in which researchers are able to explore different dimensions and perspectives of the same phenomenon. It is achieved through the employment of multiple external methods to collect and analyse data from the same topic (Fusch & Ness, 2015). Triangulation was maintained throughout this study by initially exploring the scientific literature, the use of multiple methods of data collection including speech and observation of body language and taking the notes from the reflective journal (Appendix A) into account (Cope, 2014).

**Transferability**

Transferability refers to the degree to which the results of qualitative research can be transferred to an alternative context or setting with other respondents (Houghton,
Casey, Shaw & Murphy, 2013; Polit & Beck, 2012). Findings from a qualitative study can be transferable if the results have meaning and readers can correlate the results of the study with their own personal experiences. In this study transferability was achieved through accurate reporting of participant demographics and data as well as careful identification of the complexity of both osteopathy as a healthcare option and endometriosis as a disorder as well as an honest discussion of the limitations of the project.

**Dependability**

Dependability refers to the consistency and stability of the data over time. In this research it included ensuring that interpretation is not just based on the researcher’s bias but was grounded in the data (Korstjens & Moser, 2018). This was performed by transparently describing the research steps taken from the start of the research project to the development and reporting of the findings.

Dependability was achieved in this research through an audit trail. An audit trail was a key strategy to enhance credibility and dependability of this qualitative research and to ensure that the analysis was based upon current accepted standards for a qualitative design (Korstjens & Moser, 2018; Ryan-Nicholls & Will, 2009). An audit trail was reviewed by initial supervisor Dr Alexandra Hart to ensure the same study conclusions were agreed upon. Examples of the study materials include interview transcripts, data analysis, process notes and drafts of the final report.

The audit trail included precise, consistent and reflective journal keeping; audio and text data collection; a systematic and reliable data analysis method; and disclosure of this analysis method.

**Confirmability**

Confirmability is the process of establishing that data and interpretations of the findings are not based on the researcher’s biases, but originate from the data collected (Lincoln & Guba, 1985). This reflects the degree to which the findings of the research study could be confirmed by other researchers.
Confirmability demonstrates the researcher’s ability to provide data that represents the participants’ responses and not the researcher’s biases or viewpoints (Polit & Beck, 2012; Tobin & Begley, 2004). In this study, research confirmability was achieved by demonstrating how conclusions and interpretations were established, exemplifying that findings were derived directly from the data. In reporting the qualitative research, confirmability was exhibited by providing rich quotes from the participants that depict each emerging theme.

**Qualitative Data Analysis**

Within qualitative research there are different analysis methods that can be applied through the process, depending on the nature of the data collected. Some of these methods include content analysis, thematic analysis, grounded theory and discourse analysis (Noble, 2014). Data analysis of qualitative descriptive research does not use a pre-existing set of rules that have been generated from the philosophical or epistemological, unlike other qualitative approaches (Lambert & Lambert, 2013). Analysis is data-derived and codes are generated from the data in the course of the study.

A thematic analysis was chosen as a method for analysis for this study as it uses pattern recognition to examine and extract the most important meanings and concepts from the data to develop into themes (Zarea, 2016). The thematic analysis is independent of a specific theory or epistemology (Javadi & Zarea, 2016). This thematic analysis, guided by Braun and Clarke’s (2006) paper ‘Using thematic analysis in psychology’, has been extensively used across a wide range of epistemologies and research questions (Nowell, Norris, White & Moules, 2017) and in research across a multitude of health-focused disciplines (Braun & Clarke, 2014). This is because it can demonstrate inter-rater reliability, which is a concept that can potentially be problematic throughout qualitative research (Braun & Clarke, 2013). A thematic analysis should make sense of the data rather than just basing the main research question as themes (Clarke & Braun, 2013). The initial step in any qualitative analysis is becoming familiar with the entire body of data by reading and re-reading the transcripts and any other data that is likely to be used to generate codes (Maguire & Delahunt, 2017). A ‘code’ is a word or a short phrase that represents
salient portions of the data (Saldaña, 2009). This allows the researcher to maintain small chunks of meaningful data that accurately represents the rich and complex essence of the raw data. The sorting and organising of qualitative data can be aided using software applications such as QDR Miner, ATLAS and Nvivo, which can help maintain a trail back to the original data.

Methods

The remaining part of this section will discuss ethical considerations, participant recruitment and inclusion, data collection and data analysis method.

Ethical Considerations

In qualitative description an emphasis is placed on supportive researcher-participant relationships with open-ended dialogue to fully appreciate the participants’ experience. With this in mind, measures to promote safety and wellbeing were addressed and included support for both the researcher and those who consented to be researched, this was important as conversations around suffering are a sensitive subject. (Walker, 2007).

It is necessary to take important ethical concerns into consideration when performing qualitative research including anonymity, confidentiality and informed consent (Richards & Schwartz, 2002). Considerations of ethical issues were addressed throughout the course of this research. Particular focus was placed on minimizing participant harm, informed consent, data collection, anonymity and confidentiality, data security and the right of withdrawal from the study. All due steps were taken to ensure that high ethical standards were maintained throughout the course of this study. Clear protocols for dealing with distress were put in place so that both researcher and participants could use them if necessary. The Unitec Research Ethics Committees (UREC) provided independent auditing for this research project to ensure the research proposal complied with universally endorsed ethical standards (Sanjari, Bahramnezhad, Fomani, Shoghi & Cheraghi, 2014).

An ethics application was submitted to the UREC in February 2018 and approval was granted (reference: 2017-1095) (Appendix B).
Polit and Hungler, (1999) state, to gain informed consent means that participants need to have adequate and comprehensive knowledge, enabling them to freely approve or decline participation in the research. With this in mind, details regarding the research project were provided through an information sheet detailing the outline of the study and what was required of participants. Information sheets were supplied to each potential interviewee (Appendix C). Participants who wished to be involved in the study were required to contact the researcher via phone call or email.

An initial phone call was arranged for interested participants during which the researcher provided further information regarding the nature of the research. This included informing participants in detail of what would be required of them, confirming the inclusion and exclusion criteria, stating the withdrawal information and answering any questions the potential participant may have had. After the initial informative phone call, the eligible participants were then invited to participate through an email. The initial phone call to the participant was used to ensure that they fully understood what was involved and that consent was informed.

It was recognised that recollection of the lived experience of endometriosis or a negative experience associated with osteopathic care may become distressing to not only the participant but also the researcher. The researcher recognised the importance of preparation prior to the commencement of the interviews, to allow the researcher to build confidence in their skills (Sque, 2000). The researcher learned appropriate interview techniques from her primary supervisor Dr Alexandra Hart, a qualified counsellor and experienced qualitative interviewer. These techniques and data collection methods were practised with colleagues to ensure competence before interviews commenced.

Mindful of the emotive topic, a support system was developed for the researcher, including a qualified practitioner in mental health recruited into the research process to support the researcher with any unforeseen emotions that may have emerged throughout the research project.

Smith, (1992) warns that despite efforts to predict risks before the study begins, due to the nature of the study the researcher could not predict what the interview would
uncover. This is why consent in qualitative research is commonly viewed as ongoing, and transactional. Consent in this research was gained at different points throughout the recruitment, interview and post interview stage using verbal and written consent. Before data collection commenced, a participant consent form (Appendix D), was voluntarily signed by the participant. The participant was provided time to consider the consent before signing. Participants also were informed that they had the right to withdraw at any stage.

Walker, (2007) discusses how ethical conduct can be managed not only through gaining consent but also making sure that a contact point for further information is made available. Due to the sensitive nature of the study, immediately following the interview the participants were provided with a ‘Post-Interview Information Sheet’ (Appendix E) which included the contact details of the free national and regional helpline services including Māori and Pasifika services. Interviewees who experienced any form of distress during or after interviews were to be referred to the appropriate support by the researcher and supervisor. The researcher was available to those participants who needed assistance in seeking help.

A copy of the interview transcript was provided to the participant to review and authenticate. The participant was reminded throughout the interview process that they had the right to withdraw at any stage.

**Privacy and Confidentiality**

Interviews took place at a venue of the participants’ choosing. It was ensured that it was at a convenient time and in a place that is safe for both the researcher and participants. In terms of self-safety, the researcher adhered to the lone worker policy as outlined by Work Safe New Zealand (NZ) (Worksafe New Zealand, 2016).

Because participants were recruited through their osteopath, there was initially no direct contact between the researcher and participants. Instead, eligible participants were asked by their osteopath whether they would like to take part in this study and interested participants were requested to contact the researcher.

To protect the confidentiality and privacy of participants, only the supervisor was provided with an interview timetable, including participant’s full names, addresses
and times that interviews were conducted. In other documents the names, locations and other identifying information of the participants have been identified through a number or pseudonym assigned to the recordings and transcripts.

Consent forms, audio recordings and transcripts are kept in locked cabinets at Unitec and on the researcher’s password-protected computer. This information will be held for ten years as per the UREC ethics approval for this study. After ten years all hard copy and electronic information will be destroyed.

**Participant Sample and Recruitment**

**Inclusion Criteria**

The criteria for participation for this study stated that participants were female and no younger than eighteen years of age due to the ethics of recruiting minors. Women over the age of fifty were also excluded from the study, this is the average age for menopause and symptoms of endometriosis are not as common after menopause (Manero, Royo, Olartecoechea & Alcazar, 2009; Shah, 2014; Snyder, Beets, Lessey, Horton & Abrams, 2018). Participants were required to have been diagnosed with endometriosis through laparoscopy as the combination of laparoscopy and histological verification is considered the superior standard for the diagnosis of endometriosis (Dunselman et al., 2014). In addition, osteopathic care for the management of endometriosis needed to have been received in the last 12 weeks prior to the interview, which has anecdotally been described by an osteopath as the longest period that most patients will return for regular maintenance and be able to describe the experience in authentic detail. The inclusion of this criteria was important to ensure that participants were able to share their experience of receiving osteopathic care in order to provide rich data. There were no requirements regarding participants’ ethnicity and their cultural backgrounds were welcomed to provide a diversity of perspective. However, for resourcing reasons, it was necessary to exclude participants who did not live within the North Island of NZ.

The first four women that had a confirmed diagnosis of endometriosis and had experienced osteopathic care 12 weeks prior to the interview were recruited for the study. All participants were NZ residents who were diagnosed with endometriosis through laparoscopy and have had osteopathic care for the management of
endometriosis in the last 12 weeks. The participants were between 30 and 50 years of age and were all female. All participants resided in the North Island of NZ and worked in different professions.

**Recruitment**

Purposeful sampling was used in the recruitment of participants for this study, as it can effectively identify and select individuals or groups that are especially knowledgeable about or experienced within the topic of interest (Palinkas et al., 2015).

A google search using key words such as ‘osteopathy’ and ‘women’s health’ highlighted a select number of osteopaths who advertised osteopathy for management of women’s health conditions. These osteopaths were contacted through email to recruit eligible participants. Because of patient confidentiality, potential participants who were eligible for the study were then asked by their osteopath whether they would like to take part in this study. An information sheet (Appendix C) detailing the outline of the study was provided and interested participants were requested to contact the researcher via direct phone call or email.

**Data Gathering**

**Preparing for the interviews**

Interview practice provided the researcher with opportunity to explore language, clarify the questions and ensure active listening (McGrath, Palmgren & Liljedahl, 2018). With this in mind, prior to data collection and analysis, the researcher learned interview techniques from her primary supervisor, Dr Alexandra Hart. These interview techniques were practiced with colleagues four times, which allowed the questions and techniques to be reviewed and reflected upon to ensure competence before interviews commenced. The practice interviews lasted approximately sixty minutes each and included some questions from the interview guide (Appendix F), with subsequent questions arising throughout the development of the conversation. This practice allowed for the interviewer to become comfortable with the interview techniques and for the research questions to be tested for the purpose of understanding and clarity.
Data Collection

Semi structured interviews were chosen as the most appropriate data gathering tool. In depth interviews were conducted with four participants in a location of their choosing. This included the participant’s own homes, a clinic and also church, times were arranged to suit the participants. This was the most convenient way to minimize impact on the participants’ demands from their family and work life. Undertaking the interviews in a familiar environment, at a time that suited them allowed the interviewees to feel more comfortable and relaxed, thus creating an environment more likely to provide rich descriptive data.

Due to the sensitive and emotional element of the subject, face-to-face interviews were identified as the most appropriate form of data collection. Face-to-face interviews allow for social cues, such as voice, intonation and body language to be observed which provided the interviewer with extra information to contribute to the verbal answers of the interviewees (Opdenakker, 2006).

The interviews began with open-ended questions, which provided space in which the interviewee could contribute their own perspective without limitations which may have potentially been imposed by more closed questions (Chenail, 2011). Follow up questions were curiosity driven and based upon the responses of the interviewee, in order to explore the participant’s particular experience in further depth. All participants were able to relate the real-life experiences and accounts of their osteopathic care they had received. One participant had seen the osteopath only once, and therefore her experience was limited compared to the other participants. However, the care that she had experienced was able to be explored and described in depth.

The questions put to the participants covered topics relating to experiences of; osteopathic care for management of endometriosis; osteopathic treatment for endometriosis; management of endometriosis; initial contact with osteopathy; initial impressions of osteopathy; living with endometriosis; and if or how those symptoms have changed since receiving osteopathic care. A copy of the researcher’s Interview Guide with a list of pre-planned questions is included (Appendix F), however, it is important to note that additional questions were asked during interviews.
The audio of the interviews was recorded which allowed the researcher to focus on the interview content, the verbal prompts and non-verbal communication. This audio recording also allowed for a ‘verbatim transcript’ to be produced for further reference (Jamshed, 2014). Nonverbal communication such as hand gestures was an important source of information throughout the interview as it conveyed expressive information often critical to communication (Denham & Onwuegbuzie, 2013). For this reason, a journal of field notes was kept and used soon after the completion of each interview for reflection of observations, thoughts and underlying emotions (Appendix A).

The four interviews ranged in duration from forty-six to ninety-three minutes. This provided a total of approximately 282 minutes of interview time. To ensure confidentiality of each interviewees identity the data was anonymized. Audio files were transcribed initially using a professional online software service (http://scribie.com, Scribie, CA, USA), and then subsequently were checked by the researcher against the audio recording of the interviews to ensure accuracy of the text. The transcripts were returned to each participant to allow for review. Only minor changes were requested.

**Analysis**

Thematic analysis was undertaken to identify and analyse patterns of meaning within this dataset. In this study Nvivo 12 software (QSR International Pty Ltd, Australia) was used for the sorting and organising of the data.

**Data Analysis**

A thematic analysis requires the researcher to describe an interpretative narrative about the data in relation to a research question (Clarke & Braun, 2014). Clarke and Braun (2014) explain that a thematic analysis is highly flexible in relation to the types of research questions and appropriate forms of data. It is often used to answer research questions around experiences and behaviours and influencing factors, providing a rich description of a dataset, identifying key themes. Thematic analysis allows the researcher flexibility as it is not tied to a particular theoretical framework. Therefore, it does not come with particular stipulations on how to sample and collect
data, but still provides a framework to analyse and interpret nuanced and complex data (Braun & Clarke, 2006; Braun, Clarke & Weate, 2016). For the purpose of this research, the guiding technique was Braun and Clarke’s (2006) six-phase thematic analysis design.

The different phases of the thematic analysis are non-linear processes. It is a recursive process, where the researcher fluctuates back and forth as required, throughout the different phases (Braun & Clarke, 2006). Engagement with the literature during initial stages of data collection can enhance analysis by exposing the researcher to more subtle features of the data (Tuckett, 2005). The following are phases that have been applied until the meaning of themes or ideas are internally coherent and consistent and therefore can be reported on.

Only the data that was most significant to the research topic has been included in the manuscript. These main themes provided a richer picture of the experiences of the group of participants.

Below is a more detailed explanation of each of the six phases as applied to this study.

**Phase 1: Familiarising yourself with the data**

The initial stage of data analysis helped familiarize the researcher with the depth and breadth of the material obtained from the interview process and interactions with the interviewees. Following each interview, the researcher listened to the audio recordings while reading the transcripts for further familiarization and accuracy of transcription. The researcher then ‘immersed’ themselves in the data by repeatedly reading the data in an active way whilst searching for meanings and possible patterns (Braun & Clarke, 2006). The researcher began taking notes and marking ideas for coding that could then be reflected on in subsequent phases and field notes.

**Phase 2: Coding the data to generate nodes**

Phase 2 began once the researcher had read and familiarised themselves with the data. Initial ideas and interests throughout the data had been identified and noted. Each interview transcript was imported into a labelled NVivo file to assist in generating codes. The NVivo software efficiently stores, organizes, manages and reconfigures data into nodes to enable human analytic reflection and code development (Bazeley &
Jackson, 2013; Saldaña, 2009). Codes identify segments of the data that are of interest to the analyst by reducing the raw data to its simplest form so it can be thoroughly assessed in a meaningful way (Boyatzis, 1998). To ensure saturation was achieved the researcher coded for as many potential themes as possible and therefore generated codes ‘inclusively’ (Appendix G).

**Phase 3: Collating the codes into themes**
Following completion of initial coding and collation, this phase focused on identifying broader potential themes and patterns and then collecting all data relevant to each potential theme. To assist with this, an electronically built mind map was created using the website Debategraph (Debategraph.us, UK) (Appendix H). All the codes generated from NVivo (QSR International Pty Ltd, Australia) were applied to the map. To build the map, the researcher considered the relationships between codes and then rated the relationships on importance in both directions. These relationships were guided by the interviews. This enabled a visual assessment of the codes and the importance of the main themes identified within the data. This collation of the data acted as an accurate and complex mind-map that guided the deeper analysis and discussion of the data.

Visual cluster analysis occurred once the map was completed. Within the map, there were nine larger clusters that contained both denser and strongly connected nodes (Appendix I – P).

**Phase 4: Reviewing the coded extracts and accorded themes**
Within this phase, the main themes were reviewed and refined on two levels. Firstly, to consider whether the themes appeared to form a coherent pattern and capture the contours of the coded data. Secondly, to consider the validity of individual themes in relation to the data set and whether the themes reflected the meanings evident in the data set as a whole (Braun & Clarke, 2006).

**Phase 5: Defining and naming themes**
During this phase, the researcher identified the essence of each theme, determining which aspect of the raw data each theme captured. It began with thoroughly exploring
and further refining the clusters within the nine chosen codes. Key quotes from the interviews were selected to represent the meaning for each of the themes and capture the essence for the participants. The researcher gained a clear definition of what the themes signified, the scope and content of each theme and how they would be represented in the final phase.

*Phase 6: Producing the final report*

Phase six occurred once the main themes and interconnections had been identified and involved the final analysis and write-up of the report (Braun & Clarke, 2006). Presentation of the thematic analysis required conveying a complicated story of the data by demonstrating the objectivity and validity of the analysis whilst illustrating the story that represented each individual participant within it.

**Conclusion**

Chapter Four has discussed the methodology of qualitative research as well as the thematic analysis method. The chapter outlined the theoretical and practical steps that were used in the research process as well as discussions of ethical considerations and rigour. The information in this study may be used to understand what women value in osteopathic care when managing endometriosis. Readers may understand possible implications that the findings have for the osteopathic profession as well as the wider healthcare community who manage women living with endometriosis. Information is readily available to indicate to the reader the age, experience and culture of the group of people within this study.
CHAPTER FIVE - FINDINGS AND DISCUSSION

Introduction

The aim of this study was to explore the lived experience of osteopathic care among women who have endometriosis. The findings in this study uncovered participants’ experiences of osteopathic care and the characteristics of the osteopaths that contribute to this experience. The results and discussion have been combined into one chapter in order to avoid repetition and assist the reader. Three themes will be presented as an exhaustive description utilising quotations from the participants’ narratives to illustrate key points. The themes will then be discussed in relation to current research literature.

Thematic analysis of the data revealed three core themes and 10 subthemes which will be discussed in order below.

Theme 1
Osteopathy and an enhanced quality of life
Subthemes: the experience of empowerment and the experience of self-management.

Theme 2
Characteristics of the osteopath
Subthemes: understanding the person and having compassion, building trust, making time, encouraging relaxation and joining the dots.

Theme 3
Impact of osteopathy on the physical self
Subthemes: touch throughout assessment and treatment being a positive experience, and a holistic method of assessment and treatment.
Osteopathy and an enhanced quality of life

The experience of empowerment

The participants expressed their past and current battle with the physical and psychological symptoms associated with endometriosis and how these have impacted on their quality of life. All participants had accepted that they would not find a cure for their endometriosis, so alternatively, were seeking support and guidance to manage the associated symptoms rather than relying on medication:

Participant 2: “But you get to a point where you perhaps don't want it to become a chronic condition, and/or you don't want to be put on stronger medication, so you try and find other ways that are alternative to the medical side.”

Participant 4: “I’m trying to stay away from medication and try and use more natural therapies”.

These participants who sought osteopathic care had tried other alternative options such as yoga, chiropractic and physiotherapy with no long-term success:

Participant 4: “I feel like I’ve exhausted a lot of other options in trying to manage pain, and just from the first appointment I felt different afterwards”.

These attitudes are reflected in research performed by Cox, Henderson, Wood and Cagliarini (2003) who detail the experiences of women that seek alternative care due to a dissatisfaction with orthodox medicine. This is often due to a lack of patient centred care and disempowerment. This dissatisfaction resulted in participants seeking non-medical alternatives to manage symptoms and obtain some quality of life.

Two participants reported that during the initial treatment, osteopaths explained to them that osteopathic care could not cure endometriosis, but rather that they may be able to assist with pain management. This ensured that patient expectations were realistic and helped develop trust between the patient and practitioner:
Participant 2: “I don't know how the osteopath does it, but he does say, "I can't take away endometriosis, but I can help with the scar tissue and the adhesions, hopefully helping that type of pain”.

Previous research has demonstrated the importance of identifying expectations such as pain management and how this knowledge can affect patients' overall satisfaction and contribute to a positive experience (Gerteis et al., 1993; Potter et al., 2003; Rao et al., 2000; Verbeek et al., 2004).

Participants reported that in spite of there being no cure, they received support and guidance in their everyday management of endometriosis-related symptoms. In addition, all participants noticed some relief of pain which helped to increase the quality of their everyday lives. Receiving help to go to work or spend time with their families without pain was at the forefront of the participants’ minds. Two participants reported that they would like to be able to focus on being a mother, wife or even a friend without the distraction of pain.

Participant 2: “When I came in, all I was concentrating on was my surgery, my pain, just what was going on, my tummy, everything was focused on that. But when I left, it felt like my head was clear. It was just weird. It was amazing”.

Participant 4: “Usually, the pain is at the forefront of my mind because it's always there, but I haven't been thinking about it as much and so I don't know if it's just a perception, or if I actually haven't been in as much pain after the treatment”.

Such experiences align with research indicating that those who utilise osteopathy to manage chronic pain (CP) symptoms experience improved QoL (Haller et al., 2016; Rother, Ruetz, Resch, Rother & Schwerla, 2015; Saracutu, Rance, Darren & Edwards, 2017; Tamer, Öz & Ülger, 2017).

All participants in this study had expressed a sense of powerlessness related to their initial diagnosis, recovery and management of endometriosis. Powerlessness was associated with a loss of control of the big decisions in their lives such as when and if
they would have children and undergoing a hysterectomy. All participants reported that they had no control over their pain and that symptoms could manifest when they least expected it. Previously, one participant had to manage what they express as “humiliating” symptoms in a crowded place whilst trying to manage their children. She expressed guilt as she did not have the energy to be able to play with her children.

Participant 3: “It's not just the pain, it's the rage-inducing frustration of not being able to just go and do something, especially if my daughter’s having a day when just getting out of the house would be the best thing, you know? She just would need to go to a playground, or go to a friend's house, and I do make an effort to do that as much as I can, because sometimes it is just the best thing to do. Get out of the house, even though I'm worried I'm going to leak everywhere, or not be able to carry her back to the car or something”.

Empowerment has previously been used to describe a relationship between health and power, based on the theory that empowered patients are healthier (Roberts, 1999; Wallerstein, 1992). It is also used to describe a patient who becomes ‘empowered’ through health education programmes or positive interactions with healthcare providers (Roberts, 1999). Within the healthcare field, ‘empowerment’ is an important concept with regards to patient health experience as it has the potential to improve the quality of healthcare systems (Holmström & Röing, 2010). In this study the word ‘empowerment’ was not always explicitly used by participants. However, empowerment was clearly demonstrated through increased awareness and understanding of the participant’s condition and own body:

Participant 2: “Well, he [the osteopath] is able to give me understanding of what's going on with my body, you know, because I don't know”.

Patient 3: “Like I said, having an awareness of how the disease affects the rest of my body, that's changed how I try and manage it”.

Participant 4: “It could even help you understand why you're experiencing those pains I think, if I were to continue seeing an osteopath that gives you a lot more awareness around the connections in your body, and what affects certain areas”.

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A study by Jones, Jenkinson and Kennedy (2004) revealed that women found the unpredictability of endometriosis, the lack of cure and the varied effectiveness of available treatments contributed to their feelings of disempowerment, and they felt that their lives were governed by their condition. In the present study, participants also reported having experienced a loss of empowerment because they did not feel that they were prepared for what the recovery would entail after surgery. Additionally, the emotional burden associated with having surgery on the pelvis which is a vulnerable area of the physical body affected participants:

Participant 2: “I think I wasn’t expecting to feel as awful as I did, after the surgery. Apparently it’s minor surgery. But I think the osteopath helped make me realise .... that I should have been feeling better than I was”.

Osteopaths supported empowerment through assessing the patients’ current condition, making a rehabilitative and/or management plan and providing education, increased awareness and support for any questions, trials or tribulations that arise:

Participant 1: “He helped me post-surgery, and things like that, with managing ways of improving life, hence not needing him as often, which is good”.

Participant 4: “I'd like to continue it to see where it goes and also he talked about a long-term programme for working on different areas of the body that could also help. So I'd like to see where that goes too”.

One participant expressed that she finds that osteopathic care has helped her gain some control of her life through giving her increased energy levels so she can interact and enjoy her child. She is able to have some control over her symptoms and it is something that she can use when ‘life’ gets overwhelming to ground her.

Participant 3: “I feel tired, but at least not all my energy is spent on feeling tense and painful and stuff. It's [osteopathic treatment is] like a reset. Break up the tension, release it, and then carry on”.

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Another participant described that after her hysterectomy surgery her mind was “scattered”, and she had not been given any management plan. She went to her osteopath out of desperation and he explained that surgery is a major life experience and that each person will react differently. This allowed the patient to relax and just “be”, which could potentially have reduced the likelihood of developing chronic postsurgical pain (Costa, McIntyre, Pinto, Araújo-Soares & Almeida, 2018).

There is little evidence of any broad adverse effects of a hysterectomy on a woman’s psychosocial functioning (Rannestad, Eikeland, Helland & Qvarnström, 2001). However, it has been suggested that it may sometimes result in side-effects related to pain, sexual dysfunction and psychological distress (Flory, Bissonnette & Binik, 2005). These side-effects may occur particularly if the patient has experienced pre-operative pain and anxiety (Vandyk, Brenner, Tranmer & Kerkhof, 2011) and/or previous emotional problems (Yen et al., 2008). Psychological vulnerability postsurgery is a coping mechanism but could also be an aetiological factor for CPSP (Hinrichs-Rocker et al., 2009). It is well documented that negative emotions strongly correlate with CP (Costa et al., 2018) and that patients with poor pain-coping strategies reported greater somatic pain and disability with associated inferior outcomes post-operatively (Block, Ohnmeiss, Guyer, Rashbaum & Hochschuler, 2001; Nyland, Cottrell, Harreld & Caborn, 2006; Thomee et al., 2006). Therefore, encouraging relaxation may potentially have helped mitigate the long-term psychological effects of surgery for the participants.

Participant 2: “When you are feeling anxious or whatever, then you do tense up, whereas when the osteopaths using osteopathy, it just seems to make you focus of relaxing”.

Holmström and Röing (2010) explain that the success of both patient empowerment and patient-centred care depends on how well communication occurs between the patient and practitioner. Empowerment requires the practitioner to develop educational skills to aid patients in making informed choices about their own health (Anderson, Funnell, Barr, Dedrick & Davis, 1991). In this study, one participant expressed that having an alternative option for managing pain made her feel more at ease and empowered.
Participant 2: “I think knowing that you have another option that may also help you, is really good. Because otherwise you're like, "What can I do now?" I think knowing I've done something to ease the pain, and knowing that it was endometriosis, and so obviously that was what was causing my pain, "Okay that's fine." But knowing you also got something to help you with your recovery is great, I think”.

The new experience of self-management

Developing the ability to self-manage the symptoms of endometriosis was essential for two of the participants:

Participant 1: “He was able to pull it all together and then help me around exercise, diet, like that whole package rather than just going, "Oh, we'll fix your lower back. And then we'll see you again in another week, or two weeks,” and not really knowing what was causing it”.

During their osteopathic encounter, three participants felt encouraged to explore self-management of the symptoms associated with endometriosis and were provided with education on disease management. One participant expressed that it was left up to her as to whether she adhere to the lifestyle changes, and did not experience judgement from the practitioner if she did not:

Participant 3: “When I don't do that, or I forget to, or I'm not up with it, he sort of isn't scolding. He's probably a little bit like, "Come on. Let's try and get it part of your routine so that it makes it easier to remember,” but he understands, because he's also a parent, that you don't always have time to, "All right, I need to sit down and do my stretches. I need to do my pelvic tilts," or whatever, because stuff happens, or I get to the end of the day, and I'm just so tired, and I forget”.

All four participants reported their osteopath educated them during consultations about basic pain mechanisms and the effect they can have on them both physically and mentally:
Participant 3: “Connecting those two, so that I understand, when I feel this, it's because this is happening, and that's pretty insightful, and it's really helpful, too, because then I know”.

Increasing the patients’ awareness and understanding of their physical and mental state allowed all the participants to develop confidence and trust in their own body and mind which had previously been reduced:

Participant 2: “I guess explaining that having surgery isn't just a minor thing. It's a big thing. He also did the breathing thing, and I think it helped me sort of not feel so, I don't know whether scattered was the word, my mind was just very scattered”.

Participant 3: “Having a greater awareness of how the disease affects me, I guess, has encouraged me to think of it differently and create different coping mechanisms”.

Participant 4: “I think that would help me to understand at what points in my cycle that I’m in the most pain, and how I might be able to manage that [the inflammation] better”.

Yong et al. (2013) believe that education is the key to managing pelvic pain. They explained that patients need to learn about pain theory and understand the link between mood and pain to reduce the impact on patients’ everyday lives. This is best done through the use of simple language, supplementary material, repetition and consideration of the patients’ unique environment (U.S. Department of Health and Human Services, 2012). This new knowledge helps the patients develop self-efficacy and confidence which leads to the patients believing that they have the knowledge and the power required to attain a healthier, reduced-pain life (Lorig & Holman, 2003). This theory is supported by findings in this study.

Practitioners are required to learn skills related to self-management that can be passed on to patients in order to increase their self-awareness and the understanding of their own situation. This can facilitate lasting change in the patients’ lives (Coulter et al., 2015):
Participant 4: “It could be considered as an ongoing treatment process to try and help manage your pain. It could even help you understand why you're experiencing those pains I think, if I were to continue seeing an osteopath that gives you a lot more awareness around the connections in your body, and what affects certain areas”.

One osteopath appeared to refer and encourage multi-disciplinary care:

Patient 1: “But it was good to have a diagnosis, and then he was able to advise me and refer me on to other people, like recommendations around vitamins and all sorts of other things to trial”.

The outcome of successful osteopathic care was life changing as all the participants expressed being able to take control and manage their own health needs. The efficacy of self-management was also reflected in a study by Schneider-Milo (2011), which used osteopathic techniques to achieve a significant decrease of perceived pelvic pain and an increase in some domains of health-related QoL in relation to pain, sense of control, social support, work and treatment.

**Characteristics of the osteopath**

*Understanding the person and having compassion*

Compassion can be described as being moved by another person’s suffering and wanting to help (Lazarus & Lazarus, 1991). Lown, Rosen and Marttila (2011) state that “medical care without compassion cannot be truly patient-centred”. All four participants experienced compassionate care from the osteopath through empathy, effective communication, respect and acknowledgement of the patient as an individual in their unique environment.

Compassion closely correlates with empathy and research suggests that empathy experienced in patient care can lead to increased patient satisfaction (Zachariae et al., 2003). All participants felt that osteopaths acknowledged their emotions which made participants feel listened to and allowed them to talk freely without the worry of being judged:
Participant 1: “By getting to know him, it's that I’m comfortable with him, to actually tell him all sorts of things, as well”.

Participant 2: “I’m not apologetic, but it doesn't make you feel very good, whereas, by comparison, when I told the osteopath that, and he didn't ... I mean, he probably did find it gross, but he didn't show it on his face, and that, to me, is as much about ... that's what showing empathy is about”.

Participant 3: “I don't know, just really feeling listened to, and understanding, and actually helping me to realise the impact that endometriosis has on the rest of my body”.

All participants thought that this meant that the osteopath could develop an understanding of the participant’s requirements, and therefore, tailored the consultation appropriately:

Participant 1: “The good thing I find with the osteo that I've, as I say, built rapport and trust with, is that he knows that if we need to spend half an hour talking about what's going on, we will”.

In this study all four participants had experienced a diagnostic delay of up to 15 years. This means that they have spent years with symptoms and at times they felt that they were not listened to and taken seriously by the medical community.

Participant 1: “And like, everyone just kept telling me, they're like, "There's nothing wrong with you." Well, there was something wrong with me, and it took 15 years to try and find it. And it's not really good enough, in my eyes, as a medical professional, I'm like, "We need to be doing something about this”.

The physician-patient relationship has an integral role in patient centred outcomes (Chipidza, Wallwork & Stern, 2015; Ernstmann et al., 2017; Razzaghi & Afshar, 2016) and is based upon a unique intimacy and trust (Adelman, Greene & Ory, 2000). A study by Kee, Khoo, Lim and Koh (2018) demonstrated that active listening is a fundamental component of clinical practice and positive patient experience. The
authors concluded that active listening requires a practitioner to listen empathically beyond the content into the patients’ emotions in order to appreciate their point of view (Kee et al., 2018). This is something participant 3 outlined in the present study:

Participant 3: “Yeah. I mean, someone who's not good at listening or doesn't have an interest in listening doesn't ask those kinds of questions and pay that attention, and like I said, I feel like his understanding of what I've told him of my experience is reflected in the efficacy of the treatment”.

Both patient-centred care and patient empowerment demand good communication skills and an ability to be sensitive to the needs of each individual patient (Holmström & Röing, 2010). Feeling heard seemed to be therapeutic to the participant even if it meant less treatment time being available:

Participant 1: “Well, we always sit down and discuss what's going on, and sometimes that can take five minutes, sometimes that takes half an hour. And the good thing I find with the osteo that I've, as I say, built rapport and trust with, is that he knows that if we need to spend half an hour talking about what's going on, we will. And if it means that my osteo appointment is shorter, but generally he will make the time to do a full assessment, find out what's going on. Because it helps him, and me, to know, to make a plan forward”.

Patient-centred care was such a major component of the osteopathic consultation. All osteopaths took the time to build rapport and help make the patient feel comfortable and respected, this was achieved through active listening and good communication. As research has shown that these components of a consultation can have such an effect on treatment outcome, it is not surprising that patients felt that these were memorable components to their osteopathic experience.

**Building trust**

The concept of trust is an important component of healthcare. Patients can experience feelings of vulnerability and uncertainty and can be reliant upon the knowledge of the healthcare professional (Alaszewski, 2003). Research has shown that trust in healthcare is associated with positive treatment outcomes including the patient’s perception of better care, greater acceptance to recommended treatment and
compliance and lower anxiety associated to treatment (Bernard et al., 2006; Gilson, 2003; Jackson et al., 2004; Joffe, Mannochia, Weeks & Cleary, 2003). Research has shown associations between treatment beliefs such as positive outcome expectations and health behaviour were associated with positive treatment outcomes (Von Arx, Gydesen & Skovlund, 2016; Wertli, Campello, Held, Lis & Weiser, 2017). In this study, positive treatment beliefs came from the process of building rapport and the osteopathic practitioner being honest about their skills and abilities:

Participant 4: “I believed in him telling me that osteopathy could help, which we know not being able to find anything that's helped so far, it gave me some confidence that it could make me more comfortable”.

The patient felt in control of the treatment and that it could be stopped if necessary, which was emphasised during the initial consultation:

Participant 4: “So this was all quite a lot of in-depth discussion before any treatment began, and then he explained what he was going to do, and told me that if I was in pain or uncomfortable any time then we can stop”.

Once rapport had been developed, and patients had trust in the osteopath, three osteopaths left the participant to express if there was any abnormal discomfort and gained consent for any new techniques:

Participant 1: “So that's why I say, he doesn't explain a lot, and it's probably because he now knows what I know, so we don't need to go into a lot of that detail, because I just roll my eyes at him. But he would, like if I asked him questions about it, he'd absolutely go into it more”.

Participant 2: “I've never had any bad experiences, so yeah. He's always very professional... he doesn't always speak and tell, say what he's doing, but if you ask he will. Or if he's going to do a certain procedure, he'll tell you what he's going to do. Yeah. So, yeah. It's like he's, I don't know whether I've helped with that answer, but yeah”.

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Trust is an integral component in the relationship between patients and physician and only exists when patients perceive their physician to be sincere, trustworthy, and compassionate (Doney & Cannon, 1997; Fugelli, 2001; Leopold, Cooper & Clancy, 1996; Mechanic & Schlesinger, 1996; Thom & Campbell, 1997). However, this trust appeared to be bidirectional as the osteopath seemed to trust that the patient would inform them if there was any abnormal discomfort. This bi-directional trust allowed the patient to express openly how they were feeling physically, mentally and emotionally and helped them to relax throughout the treatment believing that the osteopath will bring some relief:

Participant 4: “I guess some people would feel more comfortable with it being a female practitioner, just because with endometriosis obviously he was touching me in obviously places where people could feel vulnerable, but I felt totally relaxed with that. I didn't have any issues at all”.

Trust was built for three participants, partially due to the osteopath demonstrating their pathophysiological knowledge of endometriosis and, also the osteopathic pathophysiological and anatomical knowledge. All osteopaths could answer questions that the patient had and were able to explain the pathophysiology of endometriosis which was recognised by the patient as similar to the orthodox description:

Participant 1: “I asked him how they registered and things like that, and what they have to go through, similar to what we have to do, just because I was interested, and I guess that's partly why I trust them more than someone like an acupuncturist, because they have to meet certain requirements, and they do training, and they have to practice and stuff, and go to so much professional development and stuff like that, whereas someone with acupuncture can just stick needles into you”.

Participant 2: “Yeah, sure. He's obviously done quite a bit of research on endometriosis. He understands what it is, I guess, and that type of thing”.

Trust appears to be an important component to the therapeutic encounter. In this study, trust was developed and maintained through the osteopaths’ actions, honesty
and sincerity. This development of trust very likely contributed to the positive treatment outcomes that were experienced by the participants.

**Making time**

Research has shown that compassionate care takes both time and commitment from practitioners (Hayter, 2010). Three participants appreciated how the osteopathic practitioner did not just inquire about symptoms of pain but also about life in general. Osteopaths typically have appointments that are 30-45 minutes in duration and in this study two participants reported that osteopaths made extra time if needed. This is in contrast to the average time for a general practitioner’s appointment in New Zealand which is approximately 10-15 minutes (Crengle, Lay-Yee, Davis & Pearson, 2005). One participant expressed that this extra time is what differentiated osteopathy to other health-related consultations and that having the ‘longer’ appointments meant that the osteopath could have an in-depth discussion and assessment and still have sufficient time for treatment. This also allowed them to discuss the toll that their condition had on their overall physical and mental wellbeing. This made them feel safe, comfortable and that the osteopath was interested in the ‘whole picture’:

*Participant 1:* For me, as a medical professional, I think that's really important to take a history, because if people don't know what's going on, and they just want to jump in and treat you, they have 10% of the knowledge, when there could be something that they're missing, that could really help”.

*Participant 4:* “I feel like we talked not for an uncomfortably long time but I feel like we had an in-depth discussion before any treatment started, which made me feel like he really understood my, not concerns, but symptoms before we began anything”.

One participant recognised the importance of the assessment process that osteopaths undertake during every appointment. She understood and appreciated that this physical assessment is just as important as the verbal assessment to ensure that treatment is targeted to the tissue that is contributing and causing the symptoms being experienced:
Participant 1: “To sort of know what's going on, he always does like a full physical assessment, as well. He gets me to bend over and move around, to see what's going on. Because obviously, when you're in that much pain, you can't move that well. Like your neck's stuck in a forwards position, and things like that. Or I can't bend that far, or twist, like if my pelvis is really tight. So he assesses all of that before he even starts doing anything”.

In this study, two osteopaths adapted the amount of time allocated to a particular patient depending on what they presented with. This did not go unnoticed by these participants and is what contributed to the rapport associated with patient centred care which contributed to the patient feeling that they are the osteopaths main concern:

Participant 1: “Like I say, he's become a friend, so just the fact that he takes the time to, like when I went last week, he, the appointment's forty-no, half an hour, and he spent an hour and twenty minutes with me”.

Research has shown that the length of time spent with a physician positively correlated with medical-technical competence and was an influential factor in patient satisfaction (Anderson, Camacho & Balkrishnan, 2007; Xie & Or, 2017). Patients will even tolerate long waiting times as long as they perceive that they will receive sufficient time with their physician (Anderson et al., 2007). Interestingly, one participant in this study expressed that she did not mind if the osteopath went over or under the time allocated as she trusted that the osteopath would provide relief which was not dependent on the time spent treating.

**Encouraging relaxation**

Interestingly, three participants expressed that they did not know what the osteopath did during treatment and had not given it too much thought until exploring it in this interview. They had just experienced positive change in a safe environment, and therefore how that had occurred had not been a major concern:

Participant 1: “I've discovered that, out of today. I need to ask him more about what he does. No, as I say, I just find that it's been real helpful. I just, I don't, as I say, specifically know what he does, but it's just been really, really good, for me”.
Participant 2: “I don't know how he did it, but that's what he said he was doing, so to me that's ... I did feel heaps better, and the pain subsided. I don't know how he did that either”.

With that trust came both mental and physical relaxation, which the participants recognised as an important element to the positive therapeutic outcome:

Participant 1: “Although I don't know specifically what he's doing, and it's because now, I guess I am relaxed with him, so he doesn't need to explain exactly what he's doing. I just do as I am told”.

Participant 2: “I guess when you're feeling anxious or whatever, then you do tense up, whereas when the osteopath's using the osteopathy, it just seems to make you focus on relaxing. I guess. Then you feel less tense. I guess the breathing also helps you feel less tense. Yeah. Not as wound up. Yeah”.

Participant 3: “Yeah, and those little wee movements in the joints in my lower back, and a little bit of stretching, but not too much. Yeah. Just a lot gentler. Yeah, and a lot just, yeah, focused on, I guess, relaxing me, rather than unlocking movements, shifting and stuff. Yeah”.

Participant 4: “I definitely felt more relaxed, I think if I'd have felt uptight then it would have been harder for him to carry out his treatment maybe. If I wasn't comfortable, it probably would have shown through tension in my body and made his job a bit harder to do. Maybe, I don't know”.

Relaxation was encouraged by all osteopaths and they tailored the osteopathic treatment accordingly, using techniques to encourage relaxation. Further advice on techniques that were used during the treatment such as breathing could also be used when needed:

Participant 2: “Yeah, yeah. I think ... And I don't know whether that's the osteopath's technique or not, but he also gets you breathing as well and sort of ... Because you can come in quite tense, and I think being tense also doesn't
help your pain. So just the getting you to breath and to relax and then working on doing what osteopaths do”.

Participant 3: “He's also done ... is it cranial, the cranial thing, with finding points on my neck, just for general, I don't know, relaxation, and honestly, and relieve tension there, and one time in particular, I must have been tired anyway, but I nearly fell asleep. It was super relaxing, and yeah, just really good…”.

Relaxation has shown to be an important aspect of the therapeutic encounter for these women. Slow breathing techniques have shown to increase comfort, promote relaxation and reduce symptoms (Zaccaro et al., 2018). Therefore, it is not surprising that breathing appears to be a useful exercise that osteopaths use to encourage relaxation throughout the treatment process.

**Joining the dots**

All the participants felt that the osteopaths recognised not only the physical component of the condition, but also recognised the mental and emotional burden the condition can induce:

Participant 3: “It’s vindicating, too. Having somebody [the osteopath] who has an understanding of what I'm experiencing, you know, physiologically, and because with endometriosis, it's unseen, and people's perception of pain and things like that is relative. There's no way to measure what one woman's feeling against another woman's, because you just can't do it. There's a lot of, "Am I making this up? I feel pretty bad, but I'm not sure if it is actually bad. Maybe I just need to harden up”.

This finding is unsurprising as the general principles of osteopathy and foundations of training recognise that a specific organ or system is not isolated, but rather the entire body is recruited to overcome the effects of illness. Andrew Taylor Still (1899), the founder of osteopathy, strongly believed that all aspects of an individual, including the physical, mental, emotional, spiritual and psychological state had to be considered to ensure a successful treatment approach. Therefore, osteopaths are taught to apply a range of psychomotor and other therapeutic skills to the management of patients and their disorders.
Three participants appreciated the skill that the osteopath had at being able to recognise the different components of the ‘being’ that could have contributed to the presented picture. These participants felt that the osteopath recognised how life struggles can present themselves and have an impact on the symptoms of the endometriosis and did not just focus on the pain, but also how they are generally:

*Participant 3:* “Yeah, so it's vindicating in that way, having somebody who asks me, "How are things?" I tell him how are things, and then he can feel how things are, and that is why I feel this pain here, you know, and this area is not functioning how it should be, and that's radiating paint of blah, blah, blah, and that's why you are feeling this. It's vindicating because there is a cause and effect, you know? It's not all in my head, because man, when you've had a thing for that long, this long, you're like, "Oh, should I not just have got a thicker skin by now?" You know?.”

All the participants expressed that osteopaths had knowledge and experience to recognise physical factors and compensations that could be contributing to the symptomatic pain experienced. This meant that osteopaths would not only focus their treatment on the area of pain but rather expanded it to surrounding structures that may be affecting the function of the body:

*Participant 1:* “But as I say, you'd, well I personally feel like, looser and freer everywhere like my neck and lower back, and my hips which, because, as I say, I'm not an osteo but when he assesses me, it's like you're all twisted. Like I don't know what he does, I just go and it feels better. I can find out what he does but I don't actually know, do you know what I mean? You just kind of trust in them, that they're doing what they're doing. I mean, I do feel better, so I feel freer in my abdomen and pelvic area than I've been”.

*Participant 2:* “I don't know the background of osteopathy, so I don't know what ... But in my mind, I felt a lot better. Because you know he did my neck as well as ... I think doing that helps the tension. Sort of relieves the tension, but I think the breathing was a big thing as well”.
Participant 3: “But when I am going to him regularly, when I did post-surgery and things like that, I was doing really well, when I didn't have too mu- I mean, I did have pain on and off. But it wasn't as bad as when I haven't been for a long time. Because everything around my pelvis gets locked up, so my hips get locked up, which then affects my back, which then affects my shoulders, because obviously your body's all connected. So, and then I start getting headaches. So, and it's all, I think it's all related to my endo. Because it is better than it was, prior to the diagnosis and treatment, before I had surgery”.

Participant 4: “I laid on the bed and he had a feel around my pelvis and my hips, which he said I probably got the tightest hips he'd ever felt which was quite shocking to me I suppose. I wasn't expecting that, because to me it's just normal, I don't feel particularly tight in the hips”.

All the participants recognised that the osteopaths had received formal training and had experience in treating endometriosis:

Participant 1: “I trust them more than someone like an acupuncturist, because they have to meet certain requirements, and they do training, and they have to practice and stuff, and go to so much professional development and stuff like that, whereas someone with acupuncture can just stick needles into you”.

Participant 3: “It's like everything, a cacophony of stuff that is just assailing you, and for somebody to be able to make sense of that is really insightful, and I guess probably that's his training, that's his years of experience as an osteopath, but also just having an outsider's perspective to all of those things was pretty useful through the cycle”.

Participant 4: “He was a very ... I mean he seemed to know a lot for, he was obviously quite young, younger than me but I don't feel like that hindered his experience at all. He was very confident in what he was able to tell me”.

This was important to all the patients, and they saw it as a contributor to the overall experience that they had in the osteopathic consultation. One participant especially felt that the practitioner was confident in his/her scope of practice as she had been
referred to another medical practitioner when she was presenting with symptoms that were beyond their scope of practice. This is enforced by the Osteopathic Council of New Zealand as they require all osteopaths to understand their role of a primary care team and use the referral routes within the primary care team and hospital based services if necessary (Osteopathic Council of New Zealand, 2019).

Impact of osteopathy on the physical self

Touch throughout assessment and treatment being a positive experience

Touch is defined as coming into contact with, or to handle in order to alter, and is considered to be an important component of both assessment and therapeutic treatment (Kelly, Tink, Nixon & Dornan, 2015; Verghese, 2009). Touch not only contributes to the development of trust between a healthcare professional and a patient (Benner, 2004), but can also contribute to a reduction in symptoms such as pain, anxiety and fatigue (So, Jiang & Qin, 2008; Tabatabae et al., 2016). Physical touch was an important aspect of the osteopathic experience and differentiated osteopathic care from other alternative options for all the participants:

Participant 1: “Yeah, so, for me, personally, I find physio not that helpful in the sense that when you go to see them, they do get a full history, but I find that they don't actually really treat you, they just kind of send you home with exercises to do yourself. Like they might give you a bit of a rub here, or stretch you out, maybe. But I don't find it anywhere near as helpful as an osteo”.

All participants would have experienced touch during both treatment and the physical assessment:

Participant 3: “Well, before any treatment, I guess it's just what the standard practice to ask the patient to stand, and to sort of feel where everything is, down your back and shoulders”.

Examination and evaluation played a central role in the clinical experience. Physical assessment is a key component of the overall assessment process in most healthcare
professions, as it enhances safe and efficient patient care. Additionally, it provides a foundation for diagnosis and management (Fennessey & Wittmann-Price, 2011). For all participants examination included not only palpation for three patients, but also range and quality of movement.

Participants found it difficult to describe the experience of touch and what it was that made it such an important part of the experience. They used the words ‘heat’ and ‘energy’ to describe how it felt:

Participant 2: “It always feels ... It just ... I don't know. That's really hard to explain, because it just feels like a ... I guess it feels like. You want to know what it feels like, the heat or the, yeah? There's just sort of a sensation. Or sometimes you don't feel like anything”.

Touch was described as “gentle” and “relaxing” by three participants. Touch was always consented, with all patients feeling safe. Occasionally it was physically uncomfortable and participants experienced some associated pain. However, two participants expressed that the discomfort was short-lived and the results were worth it:

Participant 3: “He quite often manages to find areas that are really tender to touch, which radiate pain. I can feel it other places as well, so he does this thing, and is able to relieve the tension from the bit that is sore to touch, but also the bit that it's radiating to”.

Participant 4: “He said to me at any point if I wanted him to stop then he'd be happy to, and he could see me wincing a little bit when he touched my abdomen and certain areas”.

Two participants reported that levels of discomfort were monitored and techniques were adjusted if necessary:

Participant 1: “I suppose the difference was, I was post-surgical, because I was really sore. So he couldn't be as aggressive, I guess, in treating that area, because I was really sensitive”.
Participant 4: “The treatment flowed so if I was in a particular area of pain, we would stop and move somewhere else”.

Three participants were surprised with the impact and change associated with the osteopathic treatment considering how gentle it felt on the body. The participants all considered that osteopathic care contributed positively to their management of endometriosis and quality of life. They described that they felt “different” or that there was a positive “change” in symptoms after the care they received:

Participant 3: “When I walk in, I feel one way, tense as all hell sometimes, and I walk out, and I feel different”.

Participant 4: “Just that feeling that something had changed after having one appointment, changed in a positive way”.

The most common symptom that all osteopaths were treating was endometriosis associated CP, whether located in the pelvis, lower back or even the neck, and often described it as tightness or tension:

Patient 1: “But as I say.... I personally feel like, looser and freer everywhere like my neck and lower back, and my hips which, because, as I say, I'm not an osteo but when he assesses me, it's like you're all twisted”.

Patient 2: “Because you know he did my neck as well as ... I think doing that helps the tension. Sort of relieves the tension”.

Patient 3: “Feeling like I feel tight, and sometimes like my pelvis is just set in concrete, and so having somebody be able to manipulate and gently mobilise that frees up that area, and just helping to stretch it out and stuff.”

Patient 4: “So the fact that he was able to look at everything as a whole, as well as my focus on my pelvis area where I experience all the pain was quite interesting”.
The results that were experienced from the osteopathic techniques that involved touch were that physical pain decreased in all participants. Participants expressed that they felt “relaxed”, “freer” and “relieved”. Participants also became more physically and mentally self-aware and found the manual treatment relaxing:

*Participant 2*: “Immediately after a treatment, I just feel freer in my body, in my joints, in my muscles. I feel relaxed, too. That's massive”.

*Participant 4*: “Usually, the pain is at the forefront of my mind because it's always there, but I haven't been thinking about it as much and so I don't know if it's just a perception, or if I actually haven't been in as much pain after the treatment”.

Participants described osteopathic treatment as being gentle and included “manipulations”, “movement”, “stretching” and other soft tissue techniques which didn’t aggravate but rather relaxed the tissue:

*Participant 1*: “Doing real gentle movements, manipulations, whatever he does, to help loosen all the area up”.

*Participant 3*: “That was pretty illuminating, and then just to do a couple of gentle manipulations and stretches, and how much better I felt after that. Yeah”.

*Participant 4*: “You tell people you're going to see an osteopath and they think they're going to crack you into position, and straighten you all out whereas this felt a lot more gentle”.

Research has shown how ‘pleasant touch’ such as soft tissue techniques can activate certain parts of the brain, such as the orbitofrontal cortex (Francis et al., 1999). Additionally, interpersonal touch can play an important role in regulating people’s emotional wellbeing (Field, 2001; Spence, 2002). This may contribute to why the experience of touch during osteopathic care plays a critical role in the therapeutic relationship (Consedine, Standen & Niven, 2016) and why it played a central role in the clinical experience of the participants in this study.
A holistic method of assessment and treatment

Osteopathy is a healthcare approach that recognises the role of the musculoskeletal system in health and encourages optimal function of the body through a variety of manual techniques (DiGiovanna, Schiowitz & Dowling, 2005; Franke, Franke, Belz & Fryer, 2017). Holism has been described as a model that deals with health problems by taking the patients physical, psychological, social, cultural and existential states into account (Freeman, 2005). Osteopathic treatment was considered a holistic approach by the participants.

By understanding that endometriosis is a chronic condition that is complex and does not currently have a cure, the osteopaths within this study appear to have recognised and considered the different mechanisms that may have been contributing to symptoms such as pain. This comprehension may have aided in relieving some of the symptoms. The body is considered a unit of mind, body and spirit that mediates and modulates the pain response, initiating the unique psychological and physiological responses. This could partially explain the successful treatment outcomes experienced by participants in this study, even when techniques were applied to areas and tissues of the body that were sometimes away from the symptomatic area:

Participant 1: “He's doing manipulations to my spine and like, I don't know what it is that he's doing, but he does things with my abdomen, but also, as I say, loosens up anything else that might be causing me trouble, like my lower back, or my hips, or things like that”.

Participant 2: “Because you know he did my neck as well as ... I think doing that helps the tension. Sort of relieves the tension, but I think the breathing was a big thing as well”.

Participant 3: “Oh, and just how he noticed ... Well, before any treatment, I guess it's just what the standard practice to ask the patient to stand, and to sort of feel where everything is, down your back and shoulders, and look, and then to bend over, touch your toes, and then slowly pull yourself up again, and just what he was able to tell me after having done that”.

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Osteopathic treatment involved an extensive range of manual techniques including soft tissue, spinal manipulation, specific stretches, muscle energy technique, visceral technique and exercise prescription. Participants experienced changes in their symptoms immediately and one participant expressed an element of surprise at the changes considering the treatment was so gentle:

Participant 1: “Doing real gentle movements, manipulations, whatever he does, to help loosen all the area up”.

Participant 3: “To me, to my understanding, in my mind, that's a pain symptom, and yeah, I think whatever he's able to do, in releasing tension in those areas, and around those areas, and mobilizing, like stretching out those muscles and stuff so that everything can move freely as it's supposed to”.

Participant 4: “You tell people you're going to see an osteopath and they think they're going to crack you into position, and straighten you all out whereas this felt a lot more gentle”.

In summary, all participants expressed their past and current battles with the physical and psychological symptoms associated with endometriosis and how the condition impacts on their quality of life. As there is currently no cure for endometriosis, the participants were seeking support and guidance to manage the associated symptoms rather than relying solely on pain medication. The findings showed that the contributing factors to a successful treatment outcome were multifactorial and did not solely depend on the technical skill of the practitioner. Success also relied on a complex and dynamic relationship between patient and practitioner built on trust and compassion. This success was also built on knowledge of the condition and the patient centred care demonstrated by the practitioners.

**Limitations**

There are several limitations in this study. Due to the scope of this thesis, there was a small sample size which may contribute to a lack of transferability across literature. Furthermore, the four participants that were included were difficult to recruit due to practitioner and patient confidentiality. However, the interviews generated a large
amount of rich and informative data which demonstrated both depth and width in the analysis. The results of this study are not intended for generalisation in other contexts. There were no participants under the age of 20 and it is important to acknowledge that although adolescents and teenagers may also benefit from osteopathic treatment, this study cannot provide any evidence to support that claim.

A second limitation was self-selection bias related to all participants volunteering to be a part of this study. It is possible that the willingness of participants to take part in the research was a result of their positive experiences and may have influenced data. A larger study would be needed to support any claim that osteopathic treatments are beneficial for all, or even most, women with a diagnosis of endometriosis.

The primary researcher in this study was an osteopathy student and had previously observed a close friend manage the diagnosis and treatment of endometriosis, which may have led to confirmation bias throughout data collection and analysis. However, the researcher considered this and reviewed apparent risks with supervisors and received feedback as to how to undertake the interviews to minimize these biases. The researcher and her supervisors had not identified any conflicts of interest and there had been no commitment to any particular outcome from this research as the researcher has sought to only explore information on this topic and highlight the findings of this research.

Positive outcomes that were reported by participants related mostly to improvement of pain and psychological symptoms. There is no attempt to connect osteopathic treatment to improvement of other symptoms of Endometriosis.
CHAPTER SIX - CONCLUSION

This study contributes to the limited qualitative literature available on the patient experience of osteopathy for the management of endometriosis and its associated symptoms. Although there is limited research regarding the use of osteopathic care for women with endometriosis related symptoms, it is well established that those who use it to manage chronic pain (CP) symptoms experience improved quality of life. Therefore, it is not surprising that the results from this research albeit with the small number of participants, show that osteopathic care has a positive effect with pain associated with endometriosis.

Thematic analysis of the data revealed three core themes;

- Osteopathy and quality of life
- Characteristics of the osteopath
- Impact of osteopathy on the physical self

The findings showed that factors contributing to a successful treatment outcome are multifactorial, relationship-based, and built on trust and compassion. The participants stated that osteopathic care contributed positively to their management of endometriosis and quality of life. Most participants were surprised with the impact and change associated with the osteopathic treatment considering how gentle it felt on the body. The most common symptom that osteopaths treated was endometriosis-associated CP. This was treated using osteopathic manual techniques aimed to reduce tension and encourage relaxation. Osteopaths also educated participants on the pathophysiology of the disease and provided advice on self-management.

The results from this study supports further research exploring the effects of osteopathic treatment on both physical and psychological symptoms associated with endometriosis. Furthermore, it provides information on osteopathic care as a complementary therapeutic option for women as they manage this highly complex condition. Taking the symptoms of endometriosis, osteopathic treatment of CP and the excessive diagnostic delay into account, research is required on whether osteopaths are diagnostically screening for endometriosis and whether they could
possibly contribute to a faster diagnosis through referral. Further research exploring osteopathic practitioners’ experiences of managing both physical and/or psychological symptoms associated with endometriosis should also be undertaken.

Endometriosis is a highly complex condition with numerous physical, psychosocial and emotional symptoms. The impact these psychosocial and emotional symptoms expressed by those women suffering from endometriosis play on the practitioner could also be investigated.

It was predicted that participants would find osteopathic treatment beneficial for the relief of chronic pelvic pain and other symptoms associated with endometriosis. However, the data collected also gave insight into what a woman experiences during osteopathic care and her interpretation of what contributed to the treatment outcome. Information gained from this study demonstrates the importance of not only training osteopaths in osteopathic techniques for CP, but also ensuring that osteopaths have sound knowledge and experience in health psychology and an understanding of CP. This will ensure that they have the skill set necessary for the successful management of women with endometriosis. As there is currently no cure for endometriosis, support and guidance to manage the associated symptoms is required. Osteopaths could play an integral role in collaboratively managing pain associated with endometriosis, however this thesis highlights the need for further research to be undertaken within the field.
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Appendix A: Reflective Journal Excerpt

A reflective journal is an essential part of qualitative research. An entry into a reflective journal was written directly after each interview and throughout the analysis process. This is an excerpt from interview one.

19th May 2018

“Participant still struggles with symptoms of endometriosis and was uncomfortable during the interview. Participant has a very busy life with work and hobbies etc, she has a good support network not effected so often by symptoms. Couldn’t believe how long it had been before the last appointment that she hadn’t had to see the osteopath! Trust was integral to the participant and the osteopath’s higher education was an important aspect. Seemed tired with it all as has been dealing with it for a long time. Osteopath has become a friend and is seen through same social circles. Wanted to clarify that osteopath is very professional in and outside of the clinic room.”
Appendix B: Ethical Approval Letter

Dear Maadi Dalgliesh Waugh,

Your file number for this application: 2017-1095 WAUGH
Title: New Zealand Women’s Experiences of Osteopathic Care While Living with Endometriosis

Your application for ethics approval has been reviewed by the Unitec Research Ethics Committee (UREC) and has been approved for the following period:

Start date: 18 February 2018
Finish date: 18 February 2019

Please note that:

1. The above dates must be referred to on the information AND consent forms given to all participants.
2. You must inform UREC, in advance, of any ethically-relevant deviation in the project. This may require additional approval.

You may now commence your research according to the protocols approved by UREC. We wish you every success with your project.

Yours sincerely,

Nigel Adams
Deputy Chair, UREC

cc: Asher Lewis
Appendix C: Participant Information Sheet

Participant Information Sheet

**Research Project Title:** New Zealand Women’s Experiences of Osteopathic Care While Living with Endometriosis

**Programme:** Master of Osteopathy, Unitec Institute of Technology

**Project researcher:** Maadi Dalgliesh Waugh  **Contact phone number:** 0210744376

You are invited to take part in a study exploring the lived experience regarding osteopathic care among New Zealand women diagnosed with endometriosis. Whether or not you take part in this study is your choice. If you choose to take part now, but change your mind later, you may withdraw from the study at any time prior to the completion of the research project without having to give any justification for doing so.

This participation information sheet will inform you on the research project and will help you decide whether you wish to take part in it. It sets out why this research project is being done, what your participation will require, the potential risks and benefits, and whether you are eligible for the study. Please read through this sheet carefully. If you have any further questions or concerns, we will go through them with you. You do not have to decide straight away whether or not you would like to participate in this study. Before you decide, you may want to take a bit of time to talk about the study with your family, whānau, friends or healthcare providers. Please feel free to do this.

If you meet the criterion and wish to participate in this study, you will be asked to sign a consent form. A copy of both the participant information sheet and a signed consent form will be given to you to keep. Your name, contact details and any information that might identify you will be kept confidential with only researchers of this study having access to this information. All of this information will be stored in a password controlled computer file where only the project researchers will have access to it.
OUTLINE OF THIS PROJECT

This project aims to explore the lived experience of osteopathic care among New Zealand (NZ) women diagnosed with endometriosis. Information on the topic of endometriosis is extensive. However, information on osteopathic care and any effects for women living with endometriosis is scarce. This study hopes to address this gap by exploring women’s experiences of osteopathic care while living with endometriosis to increase knowledge in helping support women who are managing this highly complex condition.

WHAT ARE WE DOING?

The researcher will interview women who have been diagnosed with endometriosis through laparoscopy and have experienced osteopathic care three times within the last year. The interviews will be undertaken at a suitable place that you choose. The interviews will be audio recorded only and then transcribed using a confidential transcription service. The collected data will be analysed by the researcher and her supervisors, using qualitative methods, for common themes regarding the experience of osteopathic care among women living with endometriosis. It will then be written up as a research thesis as part of a Master of Osteopath course. The thesis will become part of the Unitec Commons held by the Unitec library.

WHAT WILL MY PARTICIPATION IN THIS STUDY INVOLVE?

This project will be discussing the experience of osteopathic care and living with endometriosis. This subject can be a potentially sensitive subject and may affect you emotionally. Therefore, as a potential participant, we ask you to reflect as this project may be a sensitive and emotional topic for you and to carefully consider the nature of this project before deciding to participate.

Upon deciding to participate, you will be required to be available for a face to face interview lasting 90 minutes which will be scheduled at a time and place that is convenient for you. The interview will be semi-structured, allowing plenty of time for you to explain your views and experiences. It will be audibly recorded using two forms of digital technology and the researcher may take notes to help keep track of information.
All information provided by you will be kept confidential and your identity will be protected. After the interview a copy of the transcript will be provided for you to authenticate. Pseudonyms will be used to preserve your anonymity within the written thesis.

If you agree to participate, you will be asked to sign a consent form. This does not stop you from changing your mind if you wish to withdraw from the project at any stage.

Your name and any information that may identify you will be kept completely confidential. All information collected from you will be stored on a password protected file and only you, the one researcher and her two supervisors will have access to this information.

POTENTIAL RISKS AND BENEFITS

The topic of this research involves recalling the lived experience of osteopathic care while living with endometriosis which can potentially be emotive topic.

If you should experience any form of distress during or after the interview you will be referred to the appropriate support by the researcher and her supervisor.

If you experience any form of distress during interviews the interview will stop and the researcher will support you to the support services available and stay with you until the distress has been resolved.

An information sheet will also be available after interviews and will include the contact details of the free national and regional helpline services should you require them. Including Māori and Pacifika services.

The potential benefits of this study will be an increased knowledge surrounding the experience of osteopathic care among women who have been diagnosed with endometriosis. This study may influence an increase of research within this area. This may influence treatment choices within osteopathy and other healthcare providers in the future, which may improve the experience of care for women with endometriosis in NZ.

WHO CAN PARTICIPATE IN THIS STUDY?
• Women living with endometriosis who can describe their experience of receiving osteopathic care.
• New Zealand resident
• Proficient in the English language
• Living in the North Island
• Diagnosed with endometriosis through laparoscopy
• Has received osteopathic care in the last 12 weeks
• Between 18-50 years of age

WHO DO I CONTACT FOR ADDITIONAL QUESTIONS OR CONCERNS?
For additional information, or if you have any queries or concerns, please contact us using the information provided:

Maadi Dalgliesh Waugh (Project researcher)
Email: maadiwaugh@outlook.com Phone: 021 0744 376

Dr Alexandra Hart (Principle supervisor) Email: ahart@unitec.ac.nz
Phone: (09) 815-4321 ext. 8919

If you require Māori cultural support, please talk to your whanau at first instance.
Alternatively, you may contact:
He Kamaka Waiora (Māori Health Team):
Phone: (09) 486 8324 ext 2324

UREC REGISTRATION NUMBER: 2017-1095
This study has been approved by the UNITEC Research Ethics Committee from 18/2/2018 to 28/2/2019. If you have any complaints or reservations about the ethical conduct of this research, you may contact the Committee through the UREC Secretary (ph: 09 815-4321 ext 8551). Any issues you raise will be treated in confidence and investigated fully, and you will be informed of the outcome.
Appendix D: Participant Consent Form

Participant Consent Form

Research Project Title: New Zealand Women’s Experiences of Osteopathic Care While Living with Endometriosis

Programme: Master of Osteopathy, Unitec Institute of Technology

Project researcher: Maadi Dalgliesh Waugh

Contact phone number: 0210744376

I have had the research project explained to me and I have read and understand the information sheet given to me.

I have the appropriate contact details and know whom I need to speak to if I have questions or concerns related to this project.

I understand that I do not have to be part of this research project should I choose not to participate.

I understand that I may withdraw at any time prior to the completion of the research project without having to give justification for doing so.

Please tick to indicate you consent to the following:

I have had the research project explained to me and I have read and understand the information sheet given to me.

I have the appropriate contact details and know whom I need to speak to if I have questions or concerns related to this project.

I understand that I do not have to be part of this research project should I choose not to participate.

I understand that I may withdraw at any time prior to the completion of the research project without having to give justification for doing so.
I understand the information I will provide will be kept confidential and none of the information I give will identify me. I understand that the only persons who will know what I have said will be the researcher and their supervisor. I also understand that all the information that I give will be stored securely on a computer at Unitec for a period of 10 years.

I understand that my discussion with the researcher will be taped and transcribed.

I understand that I can see the finished research document.

Declaration by participant:

I have had time to properly consider all of the provided information and have had any additional questions or queries answered. I hereby give my consent to participate in this research project.

Participant Name:

Participant Signature: 

Date: 

Declaration by project researcher:

I have given a full verbal and written explanation of the research project and have answered any additional questions asked by the participant.
I believe that the participant fully understands the research project and their role within it. Therefore, I believe the patient has given informed consent to participate.

Researcher Signature: ………………………………………………………………………………………
Date: ……………………………

UREC REGISTRATION NUMBER: 2017-1095
This study has been approved by the UNITEC Research Ethics Committee from 18/2/2018 to 28/2/2019. If you have any complaints or reservations about the ethical conduct of this research, you may contact the Committee through the UREC Secretary (ph: 09 815-4321 ext 8551). Any issues you raise will be treated in confidence and investigated fully, and you will be informed of the outcome.
Appendix E: Post Interview Handout

Support for women living with endometriosis

You have the right to withdraw at any stage throughout the research process. Should you require any additional information if you experience any distress or discomfort after this interview please feel free to contact the researcher or her primary supervisor directly.

Maadi Dalgliesh Waugh (Researcher)
Email: maadi@hotmail.co.nz
Phone: 021 0744376

Dr Alexandra Hart (Principle supervisor)
Email: ahart@unitec.ac.nz
Phone: 09 815-4321 ext. 8919

Where to get Information

For Free Support Services:

New Zealand Wide Helplines:
- **Lifeline**: 0800 543 354
- **Youthline**: 0800 376 633
- Māori Helpline: 0800 787 798
- Pasifika Helpline: 0800 787 799
- **Rape Crisis**: 0800 88 33 00
- Depression Helpline: 0800 111 757
- **Healthline**: 0800 611 116
- **Samaritans**: 0800 726 666
- Women's Refuge Crisisline: 0800 733 843
- Sexuality or Gender Identity Helpline: 0800 688 5463

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**OUTLine NZ:** 0800 688 5463

Regional Helplines:

**Waikato:** Woman’s refuge (07) 855 1569

**Auckland:** Auckland Women’s Centre, Grey Lynn (09) 376 3227
  North Shore Women’s Centre, Glenfield (09) 444 4618

**Manawatu:** Palmerston North Women’s Refuge (06) 354 5355
  Palmerston North Women's Health Collective (06) 3570314 or 027 854 0918
Appendix F: Interview Guide

Interview Guide and Questions

- Introduce self, thank them for their participation and taking the time to complete the interview.
- Set the scene for who is to be present and how to manage any interruptions.
- Outline the interview process: firstly administrative duties will be addressed which will be followed by the interview phase which will be audio recorded.
- Check that the interviewee has read and understood the participant information sheet, including the sensitive nature of the research and its potential to trigger psychological distress for some people. The participant will then be given a copy to keep.
- Ask for and answer any questions or concerns the interviewee may have before continuing with the interview.
- Invite the interviewee to sign 2 consent forms, one for them to keep and one that will be filed at Unitec.
- Outline the interview order and general content: “The interview will begin with an open-ended question which you will then be invited to answer. At any time you are able to pause the interview or ask for comments to be deleted from the interview”.
- Explain to the participant that their details will be kept confidential and explain any pseudonyms or numbering system that will be used. Explain that written notes may be taken throughout the interview so that points of interest can be re-introduced later on in the interview.
- Ask if the participant if there are any additional questions. Check it is now OK to begin the interview.
- Turn on the recorder and speak the date, the purpose of the interview and who is present - my name and the participant number/pseudonym.)

Interview Question Guide

1. Can you please tell me your experience of the osteopathic care that you have received?
   - Can you describe to me what is it like to live with endometriosis?
   - How do you manage your day-to-day symptoms of endometriosis?
   - How have you managed your symptoms in the past?
2. What has been your experience of it when managing the endometriosis?
   • What part does osteopathy play in your management of endometriosis?

3. Can you describe what your osteopathic appointment/treatment consists of?
   • How would you describe your osteopathic care to someone else managing endometriosis?

4. Can you tell me about your first contact with osteopathy?
   • What lead you to seek osteopathic care?
   • How did you hear about osteopathy? For management of endometriosis?

5. Can you describe to me your initial impressions of osteopathy?
   • The therapy and/or therapist?

6. Has your experience of endometriosis changed since receiving osteopathic care?
   or
   How has your experience of endometriosis changed since receiving osteopathic care?

Towards the End of the Interview

- Let the participant know we are nearing the end of the interview and ask if there are any questions or further comments.
- Close by reminding the participant of withdrawal conditions and how they can get a copy of the interview transcript and how they may respond.
- Ask if they want reminders of any of these actions.
- Remind the interviewee regarding how to contact me.
- Give the interviewee the ‘Post-Interview Handout’ with information regarding access to support or concerns.
- Thank the interviewee for their time and participation.
- Take all my equipment and go to my car.
- Make immediate notes verbally into the recorder about my impressions, feelings, observations and reflections.
- Make a note of things to remember for the next interview.
Appendix G: Nodes/Codes Master List

- Ability
- Acknowledgement
- Always
- Ask
- Assessment
- Back
- Before treatment
- Better
- Body
- Comfortable
- Connected
- Consent
- Control
- Could
- #No# cure
- Did
- Didn’t
- Discuss
- Ease
- Endometriosis
- Feeling #mind/body#
- Gentle
- Helps
- Hip
- Impact #positive#
- Interest #osteopath#
- Knowledge
- Listen
- Looking
- Management #overall symptom#
- Management #pain#
- Manipulation
- Medicine #allopathic#
- Mind
- Movement
- Neck
- Need #patient#
- Option
- The osteopath/practitioner
- Pain #patient#
- Pelvic #pain/discomfort/treatment/relief#
- Professional
- Questions #patient/practitioner#
- Recovery
- Release
- Talks
- Tell/Advice
- Tense
- Tight
- Time
- Touch
- Treat
Appendix H: Debatograph – Full Mind Map of Codes and Relationships
Appendix I: Osteopathy ‘Helps’ Code
Appendix J: Patient and Practitioner ‘Knowledge’ Code
Appendix K: ‘The Osteopath’ Characteristics Code
Appendix L: The ‘Trust’ Code
Appendix M: The ‘Relaxed’ Code
Appendix N: The Physical ‘Touch’ Code
Appendix O: The ‘Gentle’ Code
Appendix P: The ‘Holistic’ Code

Maadi Waugh - Thesis Mind Map

- Whole
- Experience
- Worked
- Body
- Approachable/Approach
- Focus
- Pain
- Alternative
- Symptoms
- The osteopath
- Treat
- Improve
- Effective
- More
- Effective

Holistic

*Note: The diagram is a visual representation of the 'Holistic' code as mentioned in Appendix P.
Full name of author: Maadi Dalgliesh Waugh

ORCID number (Optional): ............................................................

Full title of thesis/dissertation/research project ('the work'):
Women's Experiences of Osteopathic Care whilst Living With Endometriosis

Practice Pathway: Community Study

Degree: Masters of Osteopathy

Year of presentation: 2019

Principal Supervisor: Mikki Williden

Associate Supervisor: Maureen Perkins

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