A Thorn in the Flesh: The Experience of Women Living with Pelvic Surgical Mesh Complications

© Howard Lyon. Used with Permission.

Jacqueline Brown, Student ID: 3169037
2/23/2019
# Contents

Acknowledgements ................................................................................................................................. 3  
Introduction ............................................................................................................................................ 4  
  Structure of the research .................................................................................................................... 7  
Theological Underpinnings ..................................................................................................................... 8  
Background ........................................................................................................................................... 11  
Overview of Literature .......................................................................................................................... 13  
  The biomedical literature .............................................................................................................. 13  
  Two Key clinical studies ................................................................................................................ 13  
  A single lived experience study ..................................................................................................... 14  
  The relationship between mesh complications, depression, and self-harm ......................... 16  
  The New Zealand Study ................................................................................................................ 16  
  The inquiries .................................................................................................................................. 17  
  The media ..................................................................................................................................... 18  
  The chronic illness literature ......................................................................................................... 18  
Methodology ......................................................................................................................................... 22  
  Data Analysis ..................................................................................................................................... 29  
  Reliability and validity .................................................................................................................... 30  
Findings ................................................................................................................................................. 32  
  Lived Space (Spatiality) ................................................................................................................. 34  
  Lived Body (Corporeal) .................................................................................................................. 48  
  Lived Time (Temporality) .............................................................................................................. 58  
  Lived Other (Relationality) ............................................................................................................ 63  
Summary ............................................................................................................................................... 73  
Theological Reflection ........................................................................................................................... 75  
  Pastoral Response .......................................................................................................................... 77  
References ............................................................................................................................................ 81  
Appendices ............................................................................................................................................ 92  
Appendix A – Annotated Timeline Pelvic Surgical Mesh ................................................................. 93  
Appendix B – Media Reports ................................................................................................................ 99  
Appendix C – Forms of Humanisation and Dehumanisation ......................................................... 102  
Appendix D – Consent Form ............................................................................................................... 104  
Appendix E – Introducing the Women ............................................................................................... 106
Acknowledgements

I would like to acknowledge Murray Rae and the Otago University Theology Department for allowing me to undertake this somewhat ‘out of the ordinary’ Master of Chaplaincy research project. Thanks also to Annette Hannah who agreed to supervise it.

The seven women who agreed to be part of the project have my total admiration for their courage and their willingness to share their stories so that we can learn from their experiences. I hope that I have done your stories justice.

Mary James, my former Hospice colleague who has studied alongside me on her own research project has been a huge source of support and ideas. I am sure the holy water and prayers before we started tapping away at our respective keyboards helped!

My present and former work colleagues at Nelson Marlborough Health have listened to the highs and lows, taken me for coffee, and shared their own post-graduate study journeys with me by way of encouragement.

My friends and family have been a constant support. My husband Nigel held the fort at home while I travelled to do the interviews five weekends in a row, and spent periods of time away from the interruptions of home working on the analysis and write up. John (13) learned to play Fortnite quietly while mum was studying in the same office! Hannah (19) provided neck and shoulder massages, and my mum Chris, one of the early nurse researchers, was a good sounding board. Harvey, the family Labrador also played his part, the beach walks were very necessary for thinking and processing, and Harvey was a constant presence under my desk.

Te Kotahitanga Trust have funded my Chaplaincy fees each year for which I am immensely grateful, and this research could not have happened without a grant from the Nurse Education Research Foundation which paid for my airfares and travel so that I could interview the women face to face in their own homes.

Thank you also to Howard Lyon (a Mormon artist based in Utah) for allowing me to use an image of his “Thread of Faith” painting on the cover. www.howardlyon.com
Introduction

This research recognises a gap in the literature about women’s lived experiences of pelvic surgical mesh complications (hereafter called mesh complications). Without knowledge of these experiences we cannot know how to best to provide pastoral care for affected women.

The recent Australian Senate Inquiry into pelvic surgical mesh underlines the need for the present research:

The committee is acutely aware that at the heart of this serious public health issue is a group of women who have borne a great cost: the cost of living with, and trying to seek treatment for, debilitating complications that have undermined their quality of life and that of their families...this in turn has exacted an enormous toll on their emotional wellbeing.

These women have also shouldered the burden of drawing attention to their plight and mobilising action to address it. In the process, they have borne the opprobrium of those who fear transvaginal mesh devices will be banned. It has taken a great deal of courage for these women to come forward and discuss these most intimate and traumatic details in public.

My research will shed light on the experience of mesh complications as-lived by seven women who experience them, with an emphasis on revealing the breadth and depth of existential impacts that arise from this disruption to the embodied self.

Women undertake pelvic mesh surgeries for Pelvic Organ Prolapse (POP) and Stress Urinary Incontinence (SUI) in the hope of improving their lives, but many of those experiencing complications are left suffering chronic ill health, traumatised, grieving multiple losses and wondering what has become of their lives.

As a woman who has experienced mesh complications, I identify as a complete member researcher in this work and acknowledge that this has been a driving force in the decision

---


2 Rachel Siewert, *Number of Women in Australia Who Have Had Transvaginal Mesh Implants and Related Matters* (Community Affairs References Committee, Parliament of Australia, 2018), 87 Sections 5.2, 5.3.

3 Patricia A. Adler and Peter Adler, *Membership Roles in Field Research*, Qualitative Research Methods, v. 6 (Newbury Park, Calif: Sage Publications, 1987). A complete member researcher is a member of the group being studied and shares a common set of experiences, feelings and goals.
to study this topic. The advantages and disadvantages of the complete member position, or “insider” researcher role as it is also known will be discussed in the methodology section.

I am a registered nurse with more than 25 years of experience, and out of this has grown a call to chaplaincy in the healthcare context. I have been a provider of healthcare (as a nurse), a recipient of healthcare (including multiple pelvic surgeries, not all related to mesh complications) and also a provider of pastoral care in the hospital environment (as a Volunteer Chaplaincy Assistant), and consciously hold all three perspectives in balance.

Swinton says that as pastoral caregivers in healthcare we are called to care pastorally for the spirituality of human beings⁴ and Heschel says that we should see them as persons with a life story, not just passive recipients of medical expertise.⁵ We are compassionate witnesses to their triumphs and tragedies and everything in-between.

It is in the listening to these stories that we are confronted with new realities, embodied spiritual truths and deep and meaningful insights into the experience of illness. Sharing these insights with the healthcare team enables genuinely person-centred care, says Swinton,⁶ and this can then inform policy and practice on the basis of people’s lived experiences, and lifeworld.

In relation to pastoral care Abraham notes that the stories people tell are often devoid of explicit doctrinal formulations or dogmatic content, yet they are suffused with theological value.⁷

When confronted with others hardships and suffering Truter and Kotze say it is the responsibility of chaplains to take a definite ethical stance in favour of the marginalised and neglected, and against disempowering and isolating discourses and practices.⁸ This research is part of my effort to do so.

I have also come to understand that medicine specifically, and healthcare in general, is socially constructed, and this influences how we experience illness. Lay and professional medical knowledge is influenced by social, economic and political factors. Diagnostic categories and the language for describing and understanding diseases are also subject to powerful social influences. Diseases are “discovered” and professionally accepted through

---

concrete social processes. These social influences shape our perceptions of health and our experiences of our own and others’ bodies and bodily conditions, say Freund and McGuire.⁹

I have observed that spirituality permeates and integrates all aspects of health. As Muldoon and King explain,

> Previously common views have tended to regard spirituality as something purely “spiritual” in contrast to the physical, a concern of the soul rather than the body. This approach likewise saw spirituality as something interior and private, rather than relational and social, extending into the world around us. It also portrayed God chiefly as an intervening outsider, extrinsic to life and experience, whom we encountered and addressed in narrowly defined religious activities.¹⁰

Spirituality then, is not a separate aspect of experience, but is woven in and through every part of every experience we encounter in our embodiedness.

---


Structure of the research

I briefly outline some key theological underpinnings of the research, a foundation of key concepts relevant to ourselves as embodied–persons, and an understanding of health and suffering as it relates to illness.

As the women’s experiences have primarily occurred in the medical environment in the Background section I outline a brief timeline of pelvic surgical mesh, how it came to be used and when problems with its use were first identified.

In the Overview of Literature section I discuss some of the problems with biomedical research literature on pelvic surgical mesh, highlight two key clinical studies, and a New Zealand study. I discuss the sole lived-experience-based study that was found in my literature search. I look briefly at two of the key government inquiries and the role of the media in highlighting key issues. I also touch on the chronic illness literature as a source of concepts for understanding the women’s experience.

In the Methodology section I explain why I have used hermeneutic phenomenology, outline the rationale for using a questionnaire in addition to this, and describe Van Manen’s Lifeworld Existentials (Lived Space, Lived Time, Lived Body, Lived Other)\(^\text{11}\) which are used as the framework for the data analysis.

Results from the questionnaire are outlined in the Findings section, along with themes from the analysis which are grouped under the Lifeworld Existential categories. Excerpts of the women’s narratives with low level interpretation are considered under these same categories.

Finally, in the Theological Reflection I look at what the results of the research suggest in terms of providing pastoral support to women with mesh complications, drawing together the medical, the existential, and the theological, and use the parallels in the story of the hemorrhaging woman in Mark’s gospel (5:25-34) and Jesus’ response as a guide.

---

Theological Underpinnings

Embodiment

We are embodied beings. God creates Adam from the ground\textsuperscript{12} (Gen 2:7) and breathes\textsuperscript{13} into Adam’s nostrils the breath of life and he becomes a living being, an embodied being with both natural and supernatural elements, body and spirit. This is also how woman becomes embodied, although she is formed from a part of Adam’s rib (Gen 2:22).

Berry says that the formula given in this verse is not man = body + soul\textsuperscript{14} as Cartesian dualism\textsuperscript{15} would have us believe, but soul = dust + breath. He says,

\begin{quote}
God did not make a body and put a soul into it, like a letter into an envelope. He formed man of dust; by breathing his breath into it, he made the dust live...The dust, formed as man and made to live, did not embody a soul; it became a soul. Soul here refers to the whole creature. Humanity is thus presented to us, in Adam, not as a creature of two discrete parts temporarily glued together, but as a single mystery.\textsuperscript{16}
\end{quote}

Allison explains that embodiment is the normal state of human existence between conception and death. Spirit and body are an inseparable unity.\textsuperscript{17} The unity is not between an objective body and spirit, but between a \textit{lived} body and spirit, says Carel.\textsuperscript{18} When body or spirit is separated from or elevated one over the other, such as when the body is objectified, disunity is created and we are dehumanised.

Personhood

Cahill in reviewing the work of Barth says, a person does not just possess their body, they \textit{are} their body.\textsuperscript{19} As persons we are created in the image of God, the \textit{Imago dei} (Gen 1:26-27, James 3:9). Swinton affirms this, saying that the body is not the place where

\textsuperscript{12} Hebrew, \textit{adamah}.
\textsuperscript{13} Hebrew, \textit{neshama}. This word for breath is reserved for God and human beings.
\textsuperscript{14} The terms soul and spirit are used interchangeably here. Soul tends to be favoured by older commentators, modern commentators favour spirit.
\textsuperscript{15} Cartesian dualism comes from the work of philosopher Renee Descartes who proposed a split between body and mind, effectively a mind-body dichotomy.
personhood is produced, but the medium through which it is lived. As such personhood is situated within the life of human beings. Essentially, what we do to the body, we do to the whole person.

Cassell defines a person as, “an embodied, purposeful, thinking, feeling, emotional, reflective, relational, human individual always in action, responsive to meaning, and whose life in all spheres points both outward and inward.”

Buber describes two modes of interaction between persons, the “I-It” relation, where there is a detached relationship between subject and object, a lack of reciprocity and experiencing things in a piece-meal way. The “I-Thou” relationship is where one encounters another with one’s whole being. Both types of relations are necessary for our existence. The most significant I-Thou relationship described by Buber is the relationship between ourselves and God, or what he calls the eternal Thou.

Health as strength for life

Barth defines health as being, “the power to be as man exercised in the vital functions of soul and body,” and as having “strength for life”. He defines sickness as the impairing of this power.

Sickness is a reminder of our mortality. The bible tells us that sickness and suffering occurs because we live in a fallen world, and this is not the way it is meant to be. Paul emphasises a proper perspective on suffering in 2 Cor 4:16-18, that being that we are to remain hopeful as although our outer nature is wasting away, our inner nature is being renewed every day, our suffering is temporary, and ultimately preparing us for eternal glory.

While we have this eschatological promise and others like it, in the present life Messer points out that there is pain and disease that may not be cured, and must be endured. Rambo describes this as living in the place between passion and resurrection.

---

20 Swinton, Dementia, 155.
23 In contemporary language, “human”, that is both male and female.
25 For example, in the future mourning and crying and pain will be no more (Rev 21:4).
27 Shelly Rambo, Spirit and Trauma: A Theology of Remaining, 1st ed (Louisville, Ky: Westminster John Knox Press, 2010). Rambo describes this as living on, of experiencing a death but not knowing if and how life will
When pelvic surgical mesh was first introduced it was thought to be the panacea that would end women’s suffering with POP and SUI. The following section describes how this panacea instead became a source of man-made suffering.

arise from the death, based on Alan Lewis’ study of Holy Saturday, which she develops in Chapter 2, “Witnessing Holy Saturday”.
Background

Pelvic surgical mesh is most often used to repair Pelvic organ prolapse (POP), and Stress urinary incontinence (SUI).

Pelvic organ prolapse occurs when there is weakening of the muscular and connective tissues of the pelvic floor and a pelvic organ or organs descend in the pelvis beyond their normal anatomical range of movement. Many women have no symptoms, but women with symptoms may experience a heavy dragging sensation, or feel as if there is something in the vagina.

Stress incontinence occurs when the pelvic floor muscles and other tissues that support the bladder and urethral sphincter (which controls the release of urine) weaken. Sneezing, coughing, bending, lifting and other activities that increase intra-abdominal pressure cause urine leakage.

Traditional POP repair involves reinforcing tissues with sutures and/or suspending the prolapsed organs with non-dissolving sutures, or in the case of SUI using a strip of the woman’s own tissue (commonly called a pubovaginal sling) to support the bladder neck and urethra. These repairs were quoted in the literature as having a high failure rate, with around 30% requiring re-repair, sometimes multiple times. However more recent research shows that this may have been overstated, sitting closer to 10% failure, inadvertently leading to the rapid adoption of surgical mesh.

Contemporary pelvic reconstruction techniques aimed to improve on traditional methods with the use of surgically implanted meshes to reinforce the weakened tissues. Anatomical failure rates were reduced; however the mesh, which was originally designed for abdominal hernia, caused more frequent complications when used in the thinner, more mobile tissues of the vagina.

By 2008 there was evidence of women experiencing a range of complications such as mesh erosion through the vagina (also called exposure, extrusion or protrusion), pain, infection, bleeding, and pain during sexual intercourse (dyspareunia), organ perforation, and urinary


30 Siewert, *Number of Women in Australia Who Have Had Transvaginal Mesh Implants and Related Matters*, Section 4.46 findings also support this assertion.

31 Because it was originally designed for abdominal hernia the impact on sexual function was not considered by the US Food and Drug Administration when it began to be used in the female pelvis.
problems. There were also reports of recurrent prolapse, neuro-muscular problems, vaginal scarring/shrinkage, and emotional problems.⁳²

In 2016 the US Food and Drug Administration (FDA) reclassified transvaginal mesh for POP from class II (moderate risk) to class III (high risk) and required manufacturers to provide more information. In November 2017 the Australian Therapeutic Goods Administration (TGA) suspended the use of POP mesh indefinitely, and in December 2017 under a Labour: Greens coalition government, NZ followed suit.⁳³

To better understand the history of pelvic surgical mesh and the associated political, ethical and medical device industry factors see the annotated timeline, Appendix A.

---

³³ The New Zealand regulator Medsafe also suspended the use of one brand of SUI mesh sling.
Overview of Literature

The biomedical literature

Goldacre points out that historically in medical research there has been a trend not to publish, or to incompletely publish unfavourable studies (known as dissemination bias). This affects medical practitioners being able to make decisions about treatment.

There was no clinical trials evidence for 61 devices for POP at the time of their approval by the FDA. Results of the first randomised clinical trials were not publically available until a median of five years, with a range of 1-14 years after the devices were approved.

The delayed availability of accurate clinical data, and lack of comparability between studies was a key contributing factor to the huge number of women worldwide, estimated to be in the hundreds of thousands, now experiencing mesh complications. This was also noted by the Australian Senate Inquiry.

The focus of the literature search was primarily women's perspective or lived experience, and secondly recent large scale peer reviewed studies that have informed the mesh debate.

A search of PubMed using the terms “pelvis or pelvic and/or mesh complications” was undertaken, along with variations of these terms substituting the words surgical, transvaginal, polypropylene, tape, sling, problems, lived experience, experience and quality of life. The aim was to use a range of terms that might elicit any research on, or aspects of, lived experience.

I looked at articles ranging from 2002 when to my knowledge pelvic surgical mesh was first used in NZ, to the present day.

Two Key clinical studies


There is a growing body of literature documenting mesh complications, the most recent and rigorous being the PROSPECT study (PROlapse Surgery: Pragmatic Evaluation and randomised Controlled Trials) which compared standard (native tissue) repair, standard repair augmented with mesh, or biological graft\(^{37}\) in parallel. Following 1352 women for two years they found that, “augmentation of a vaginal repair with mesh or graft material did not improve women’s outcomes in terms of effectiveness, quality of life, adverse effects, or any other outcome in the short term, but more than one in ten women had a mesh complication.”\(^{38}\)

An English study looked retrospectively at first-time SUI procedures in 92,246 women over an eight year period. The complication rate was 9.8% within five years of the mesh procedure. The risk of readmission for complications was highest within the first two years, with some women requiring up to six mesh-related readmissions.\(^{39}\)

**A single lived experience study**

Only one study was found that specifically set out to ascertain women’s lived experience of vaginal mesh complications. In this 2014 study by Dunn, Hansen, Egger, Nygaard, Sanchez-Birkhead, Hsu and Clark,\(^{40}\) telephone interviews with 84 women who had received treatment for pelvic mesh complications, were conducted a mean of four and a half years post implant surgery. The purpose of the study was to describe how women experience vaginal mesh complications after optimised treatment by tertiary level urogynaecologists, which included additional support from a pelvic pain specialist, and women’s health physical therapists. The goal of analysis was to humanise the experience as personal, contextual and embodied.

The women were asked two open-ended questions about their experiences with mesh complications. The authors found that the mesh complications caused both physical and

\(^{37}\) Where tissue is harvested from the woman herself (autograft), a cadaver (allograft), or animals such as pigs (xenograft), processed, sterilised and implanted to support prolapsing tissues.

\(^{38}\) Cathryn MA Glazener et al., “Mesh, Graft, or Standard Repair for Women Having Primary Transvaginal Anterior or Posterior Compartment Prolapse Surgery: Two Parallel-Group, Multicentre, Randomised, Controlled Trials (PROSPECT),” *The Lancet* 389, no. 10067 (January 2017): 381, https://doi.org/10.1016/S0140-6736(16)31596-3. This study in particular has driven changes to the National Institute for Health and Care Excellence (NICE) guidelines with the draft guidelines released in 2018 now recommending that vaginal mesh surgery only be used as a last resort.


emotional pain in addition to the original pelvic floor dysfunction, and had a significant impact on women’s quality of life.

The women followed one of three recovery trajectories reflecting the impact of mesh complications on their everyday lives:

1. **Cascading Health Problems** – the women expressed experiencing a spiral or cascade of health problems attributed to the mesh complication that left them feeling they had run out of options to regain their health.

2. **Settling for a New Normal** – the women who once considered themselves healthy, now believed they were unhealthy. They described a sense of not returning to the state they were in before mesh surgery.

3. **Returning to Health** – the women described a resolution of symptoms and issues, although minor lingering symptoms persisted for some women, their overall trajectory of recovery was still positive.

The majority of the women in the study fell into the Cascading Health Problems and Settling for a New Normal categories. The women felt that they would not have gone through with the surgery if they had understood the risks.

The following chart from Dunn et al. outlines the main themes and the overlap between trajectories.\(^41\)

\(^{41}\) Dunn et al., 132.
The authors contrasted the experience of women awaiting surgery for POP, which included role limitations, poor sexual function, restricted physical activity, and decreased self-esteem, with their findings showing that the severe pain, despair, and permanent loss of physical and socioemotional health among women with mesh complications is notably amplified.

They highlighted the women’s degraded physical and socio-emotional health, and found that many women continued to experience mesh complications even after their surgeons believed that they had been successfully treated. They recommended ongoing research to improve the safety of vaginal mesh procedures, development of a range of holistic therapies for treating women with mesh complications, and that surgeons recognise and acknowledge the emotional journey that women are on. 

The relationship between mesh complications, depression, and self-harm

A retrospective Canadian study by Welk, Reid, Kelly and Wu published in 2019 looked at how many of the 57,611 women in Ontario, Canada between January 2004 and December 2015 had mesh complications requiring surgical intervention and evidence of depression or self-harm. The study showed in the sample of 1586 women that the risk of new onset depression was 21% higher for women requiring corrective surgery compared with women who did not. The risk of self-harm was also higher for these women. Welk et al. conclude, “When managing women with complications surgeons should be aware of the potential serious psychological implications of their complications.”

Like most of the aforementioned studies, the majority of clinical studies looking at mesh complications are retrospective. There are few prospective studies that follow women with mesh complications beyond two-three years, although a prospective New Zealand study followed women for five years.

The New Zealand Study

---

42 Dunn et al., 135. In a companion article, Brooke et al outline that of the women in the study 71% were better and 29% the same or worse 2 years after multidisciplinary management of their symptoms. 45% of the sexually inactive women in the study reported being sexually inactive due to their complications. Brooke L. Hansen et al., “Long-Term Follow-up of Treatment for Synthetic Mesh Complications,” Female Pelvic Medicine & Reconstructive Surgery 20, no. 3 (2014): 126-30

This study aimed to assess long term surgical outcomes and complications of vaginal mesh for prolapse using a prospective approach with long-term follow up, contrasting two meshes for POP. Seventy three of 158 women completed long-term follow up at five years. The study describes an overall extrusion/exposure rate of 15.8%, and success rate of 74% and 81% for the two meshes used after accounting for recurrences and other complications.\(^4^4\)

The study only outlines bodily complications, and does not describe the experience of those women for whom the surgery was not considered a success.

Much of the biomedical literature on pelvic surgical mesh refers to successful anatomical outcomes, with the underlying assumption that if the body functions well so does the person. However, clinical data is not able to fully represent the reality of a person’s experience. Some of the government enquiries and media reports have been more successful in this respect.

The inquiries

**The Scottish Independent Review**

The Scottish Independent Review of the use, safety and efficacy of transvaginal mesh implants in the treatment of SUI and POP in women occurred in response to a petition to the Scottish parliament by affected women. The final report was published in March 2017.\(^4^5\)

The Review expressed concern that some women had felt they were not believed when they presented with complications, and that this had increased the time before remedial intervention had taken place.\(^4^6\)


\(^4^6\) After the Oct 2015 interim report there were allegations of missing evidence, and three review board members resigned. A review was undertaken and identified “systematic” failings in the way the review had been run. These were reported by BBC Scotland online, https://www.bbc.com/news/uk-scotland-45982333. The report highlighted the need for patient-centred care, mandatory reporting of adverse events, improved informed consent, further studies on the long-term impact of mesh surgery, new data codes to track the use of mesh, developing pathways for the treatment of complications and that the current evidence did not indicate any additional benefits from the use of mesh over native tissue repair. The Review advised that transvaginal mesh procedures should not be offered routinely.
The Australian Senate Inquiry

The Australian Senate held an inquiry into transvaginal surgical mesh, with the Community Affairs Reference Committee inviting written submissions, receiving more than 550. Women were also given the chance to give oral submissions at hearings in four cities. Inquiry findings were published in a report in March 2018 utilising excerpts of the women’s narrative, and will be referred to directly or footnoted throughout the findings section.47

The media

The media, particularly in the UK, but also in Australia and New Zealand, has successfully highlighted some of the key issues along with some more tabloid-style reporting of individual women’s stories. As a result these stories are not always given the attention they deserve despite their reflection of the lived experience of some of the more affected women.

Holstein and Gubrium say that the media has a significant role to play in agenda setting and publicising campaigns for and against recognition of clinical conditions. They say, “In themselves the media do not provide the adjudication of contested entities, but they can help create a cultural context and to frame the debates though which medical, legal and lay interests are negotiated and contested.”48

This is evident in a selection of articles from Australia, NZ and the UK obtained via Google Alerts, see Appendix B.

It is clear from these examples that the media has very much framed the debate, covering socio-political interests, women’s lived experience, and the various inquiries and legal cases in progress. They’ve raised system, gender, sexual, and social issues, and been key in bringing these to the attention of key stakeholders. Without the media interest it is doubtful that actions taken to address some of the issues raised would have eventuated.

The chronic illness literature

47 Siewert, Number of Women in Australia Who Have Had Transvaginal Mesh Implants and Related Matters. The purpose of the inquiry was to identify how many women were adversely affected, look at what support they received, consider information provided to doctors and surgeons and examine the role of the Therapeutic Goods Administration (TGA) in approving and monitoring mesh devices for use in Australia.
Much of the as-lived reality of disability and illness is not found in biomedical literature whereas the chronic illness literature reflects the as-lived experience of illness and disability over time. Due to the chronicity of mesh complications, the chronic illness\textsuperscript{49} literature which tends to be less recent, but seminal, is a rich source of concepts that can help understand the lived experience of mesh complications.

Toombs, who lives with Multiple Sclerosis, says that we actively engage in the world through the medium of our bodies,


\begin{quote}
\textit{“Living with permanent incapacity represents a distinct way of being-in-the-world, a way of being that affects one’s sense of self, one’s relationships with others, one’s ability to interact in (and with) the surrounding world, one’s family and professional life, one’s ability to exercise control and to be autonomous and one’s relationship with one’s body.”}\textsuperscript{50}
\end{quote}

I will introduce three key concepts relevant to the experience of women living with permanent disability due to mesh complications.

Firstly, Paterson’s Shifting Perspectives in Chronic Illness model\textsuperscript{51} expands on the work of Drew Leder, describing how when we are well our awareness of bodily function recedes into the background, \textit{disappearing}, and we have a sense of control over our lives. However when we are unwell our awareness of bodily function comes to the foreground, or \textit{dys-appears}. At these times we may have a sense of powerlessness, especially when the illness or bodily impairment persists, such as in chronic illness.

Leder says that when the body \textit{disappears} in times of wellness the body may be experienced as apart from the self, however when the body \textit{dys-appears} in times of illness it may be experienced an “alien” thing, or something within which one is trapped.\textsuperscript{52}

We can fluctuate, or shift between the \textit{disappearing} body and the \textit{dys-appearing} body for example, during exacerbations of symptoms, when receiving a diagnosis, undergoing surgery, or discovering a new bodily limitation.

\textsuperscript{49} Chronic illness is defined as any disorder that persists over a long period and affects physical, emotional, intellectual, vocational, social, or spiritual functioning. Mosby, Inc, ed., \textit{Mosby’s Medical Dictionary}, 8\textsuperscript{th} ed (St Louis, MO: Mosby, 2009).


\textsuperscript{52} Drew Leder, \textit{The Absent Body} (Chicago: University of Chicago Press, 1990), 82, 87.
Secondly, chronic ill health predisposes to loss that is much more diverse than simply loss of bodily function. Doehring, a pastoral theologian, talks about the importance of assessing loss as part of the pastoral caregiving role, and outlines six categories of loss. In chronic illness we may experience one, or all of these types of losses: Material, Relational, Intrapsychic, Functional, Role, and Systemic loss.

Doehring says the more types of losses a person experiences the more complicated their grief will be. She says that grief-related emotions become disenfranchised when they cannot be openly expressed and socially validated. The degree of suffering caused by the loss varies from person to person depending on the individual context and Stewart and Shields highlight that the emotional sequelae to losses in chronic illness may be similar to those experienced after a death.

Just as physical wound healing can be hindered by complications such as a prolonged period of inflammation, so too recovery from loss can be hindered by complications producing prolonged distress, says Shear. This is known as complicated grief. Jackson says the goal is

---

53 Paterson, “The Shifting Perspectives Model of Chronic Illness.”
55 Doehring, 74, 77. Material losses are extrinsic and relate to losing assets. She identifies that where these losses relate to new disability that prevents access to valued places that the loss can be huge. Relational loss describes the ending of possibilities for intimacy on multiple levels; physical, psychological, intellectual, aesthetic, recreational, spiritual and sexual. Intrapsychic loss has to do with the loss of a symbol or ideal that is associated with persons, places and things that are important in a person’s inner world. Functional loss involves the loss of bodily function. Doehring says it often involves a shift from independence to dependence on others, as well as the intrapsychic losses that accompany this. Role loss relates to the loss of a particular role, such as family roles, work roles, even therapeutic relationships such as those between patients and health practitioners. Systemic loss is, as the name suggests about changes in family systems, communities of faith, or other organisations.
not just to learn to accept losses and limitations, but also to be able to transform the experience into something liveable and bearable with a focus on what can still be.\textsuperscript{58}

Thirdly, Todres, Galvin and Holloway propose a conceptual framework of the dimensions of humanisation in which they suggest that each dimension be imagined as a spectrum of possibility rather than an either-or polarity.\textsuperscript{59} I posit that the forms of humanisation they outline are in fact key components of pastoral care.

<table>
<thead>
<tr>
<th>Forms of Humanisation</th>
<th>Forms of dehumanisation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Insiderness</td>
<td>Objectification</td>
</tr>
<tr>
<td>Agency</td>
<td>Passivity</td>
</tr>
<tr>
<td>Uniqueness</td>
<td>Homogenisation</td>
</tr>
<tr>
<td>Togetherness</td>
<td>Isolation</td>
</tr>
<tr>
<td>Sensemaking</td>
<td>Loss of meaning</td>
</tr>
<tr>
<td>Personal journey</td>
<td>Loss of personal journey</td>
</tr>
<tr>
<td>Sense of place</td>
<td>Dislocation</td>
</tr>
<tr>
<td>Embodiment</td>
<td>Reductionist body</td>
</tr>
</tbody>
</table>

(See Appendix C for expanded, annotated chart).

Todres et al. also acknowledge that there may be times when what they have identified as dehumanising practices are necessary for effective care, and explain that they are not presented as “ideal types”, but “touchstones” for awareness when considering the complexity of lived situations.

They emphasise that dehumanisation occurs when any one or more of the humanising dimensions are obscured to a significant degree.\textsuperscript{60}

Hall and Hall say that experiencing an accumulation of dehumanising factors in the medical space increases the likelihood of experiencing medical trauma.\textsuperscript{61}


\textsuperscript{60} Todres, Galvin, and Holloway.

Methodology

Entry issues and ethical considerations

I sought approval for the study from the Otago University Human Ethics Committee – approval no: H17/142, approved on 22 January 2018.

All women were telephoned initially to ensure that they met the following criteria:

Inclusion criteria

- currently experiencing pelvic mesh complications
- have or have had implanted polypropylene mesh in the pelvic area (E.g. anterior, posterior, mid-urethral sling, sacrocolpopexy)\(^{62}\)
- have an accepted Treatment Injury claim with ACC
- sufficiently well to be able to commit to the research process

Exclusion criteria

- had primary mesh implantation surgery at Nelson Marlborough District Health Board.\(^ {63}\)

The women signed a standard Otago University consent form (See Appendix D) which stated that they could withdraw from the research at any time. In the first contact by telephone they were given the opportunity to ask any questions, reassured that their anonymity would be protected, and that they would get to check, and amend the content of the interview transcripts.

Two women with diagnosed Post Traumatic Stress Disorder were questioned gently about how they felt they would cope with the interviews, and all were made aware that they could have a support person present if they wished.

Contact by email, and text was maintained with the women throughout the study, initially fortnightly after the interviews, then monthly. This gave an opportunity for them to raise concerns, have questions answered, and keep up-to-date with the study’s progress.

---

\(^{62}\) Anterior refers to mesh implanted in the anterior wall of the vagina to prevent prolapse of the bladder into the vaginal space, similarly posterior refers to mesh implanted in the posterior wall of the vagina to prevent prolapse of the rectum into the vaginal space. Sacrocolpopexy is a procedure using a strip of mesh to suspend the prolapsed vault of the vagina after hysterectomy.

\(^{63}\) As I currently work for NMDHB it would be a conflict of interest to interview women whose surgery had been performed at NMDHB.
Participants

Seven women living with pelvic mesh complications were enrolled in the study using homogeneous criterion sampling. Members of the Physiotherapy NZ Special Interest Group in Pelvic floor disorders were contacted by letter, and email (where there was no physical contact address available) with information about the research and asked to pass it on to clients with pelvic surgical mesh complications.

Participants were only included if they had an accepted Accident Compensation Corporation (ACC) Treatment Injury claim so at the time this gave a potential pool of more than 470 women who had a POP or SUI surgery since 2005. These were women had an average age of 56 years, and ranged from 20 to 84 years. 86% were European, 6% Maori and the remainder Asian, Pacific and other. The highest percentage of surgeries were for POP (50%), followed by combined SUI and POP (30%), and lastly SUI (20%).

In comparison, the profile of the women I enrolled in my study is as outlined below:

<table>
<thead>
<tr>
<th>Pseudonym</th>
<th>Age Range/yrs</th>
<th>Mesh Surgery Type</th>
<th>Initial surgery</th>
</tr>
</thead>
<tbody>
<tr>
<td>Lisa</td>
<td>50-59</td>
<td>Anterior/Posterior/TVT (SUI and POP)</td>
<td>2006</td>
</tr>
<tr>
<td>Julie</td>
<td>50-59</td>
<td>TVT (SUI)</td>
<td>2014</td>
</tr>
<tr>
<td>Ruth</td>
<td>60-69</td>
<td>TVT (SUI)</td>
<td>2008</td>
</tr>
<tr>
<td>Beth</td>
<td>40-49</td>
<td>Sacrohysteropexy and Burch Colposuspension* (SUI and POP)</td>
<td>2002</td>
</tr>
<tr>
<td>Gloria</td>
<td>60-69</td>
<td>Anterior/Posterior/TVT (SUI and POP)</td>
<td>2008</td>
</tr>
<tr>
<td>Penny</td>
<td>50-59</td>
<td>Anterior/Posterior (POP)</td>
<td>2008</td>
</tr>
<tr>
<td>Donna</td>
<td>50-59</td>
<td>Anterior/Posterior/TVT (SUI and POP)</td>
<td>2008/2010</td>
</tr>
</tbody>
</table>

*Burch Colposuspension is a mesh-free procedure for SUI but often utilises permanent synthetic sutures. It is a procedure that was done before the rise of mid-urethral tapes (mesh).

---

64 Homogenous criterion sampling relates to selecting a small group of participants who have experienced the same phenomenon, and who meet certain criteria for inclusion.
65 Based on accepted Treatment Injury claims, which does not include pending claims or those who have not made a claim.
All the women were of NZ European ethnicity; their average age was 49 years, ranging from 43 to 69 years of age. Four of the seven women (57%) had SUI and POP combination surgeries, one out of seven (14%) had POP only, and two out of seven (29%) had SUI only.

All agreed to be interviewed in their homes. I received a grant from the Nurse Education Research Foundation which supported air travel and accommodation for me to travel to the women. This meant they were in their own environments, had access to facilities (e.g. toilet, comfortable seating), and were more likely to feel safe and relaxed. See Appendix E for brief introductions to the women.

The insider perspective

My first-hand experience of mesh complications was disclosed to participants in the information sheet (Appendix F) and again verbally during the first telephone contact. My story is already in the public arena having been published in a nursing journal, and posted on the Mesh Down Under website with permission in 2014 (See Appendix G).

In terms of Dunn et al.’s trajectories I sit within the Returning to Health trajectory, having had my mesh removed, and having made a good recovery, (although not without limitations). See the Venn diagram in the Findings section which positions the women in the different trajectories.

Radley and Dua advise that clinical interview data is prone to inaccuracy and non-disclosure due to the multifaceted and taboo nature of pelvic floor disorders so being a complete member researcher and using phenomenological methodology helped counter this.

While complete member researchers may sacrifice some objectivity, the depth of the information they are able to gather is considered a valuable compensation. Kerstetter says that all researchers fall somewhere on a continuum between complete insiders and complete outsiders. Often complete member/insider researchers are able to gain the full openness of their subjects to an extent that other researchers cannot. Radley and Billig

68 Dunn et al., “Changed Women.”
suggest that whether or not a researcher gets the private or public account depends on the interviewer relationship.\textsuperscript{71}

My own experience negated the need for women to explain what mesh is, how it is used, how and why complications occur, and allowed us to go right to the heart of their experience from the outset of the interview. In this way I believe I was privileged to hear women’s private accounts.

\textbf{Approach}

Reflection on lived experience is retrospective, it is reflecting on an experience that has already been lived through. While the women in my research continue to live the experience, this study reflects on their experience prior to interview.

Wilkinson says the voice of suffering people can be silenced by translating their experience into the language of science and technical expertise.\textsuperscript{72} In light of this, to best understand the essence of the lived embodied experience of these women I used a hermeneutic phenomenologic approach which explores how the women describe, interpret and make meaning of what has happened to them.

Hermeneutic phenomenology\textsuperscript{73} takes a “natural attitude” to describe and interpret the relationship of human beings with their “lifeworld” in contrast to a reductionist scientific attitude which seeks to analyse, predict and explain. A lifeworld approach aims to remain open to what may appear in the research that was formerly concealed.

The concept of lifeworld (\textit{Lebenswelt} in German) originates from the work of Husserl.\textsuperscript{74} Van Manen describes the lifeworld as the lived world, known through our bodies (embodied) as experienced in everyday situations and relations,\textsuperscript{75} the world that we commonly take for granted. The person’s unique lifeworld is inhabited from a first person perspective rather

\textsuperscript{73} Bracketing prior assumptions and preconceptions is important in descriptive phenomenology, but prior experiences can become sources of knowledge and sensitise the researcher to the meanings that might be presented in the narratives of participants in hermeneutic phenomenology.
\textsuperscript{74} Husserl was a German philosopher and one of the forefathers of phenomenology.
than a third person perspective, and says Marcum, is the world through which “meaning is imparted to life.”

Van Manen outlines four existentials at the heart of every human experience and says the existentials can be differentiated, but not separated.

- **Lived Space** (spatiality) is about ‘felt’ space, more than just a geographical location or physical space. It is how we experience the spatial dimensions of our everyday existence.

- **Lived Body** (corporeality) relates to how we are always bodily in the world and how we experience our bodies in everyday life.

- **Lived Time** (temporality) relates to subjective time rather than objective time. It is about how the past, present and future make up the horizons of a person’s temporal landscape and sense of continuity. It includes how we experience ‘telos’, our wishes and the plans and goals we strive for.

- **Lived Other** (relationality) relates to our social world and how we relate to others in the world in the inter-personal space. It also includes how we relate to and experience the absolute Other, God.

Illness, disease, and associated disability may cause dysfunction of the physical body, but even more important to consider is their disruption of the embodied person’s lifeworld.

The qualitative methodology of phenomenology mirrors theological reflection in that it asks what is happening? Why is it happening, and what does it mean? Theological reflection contributes to meaning, and adds, how will we respond? The two complement each other when exploring complex human situations and experiences, in this case women’s experiences of living with mesh complications.

**Questionnaire**

The women completed a modified form of the International Consultation on Incontinence Modular Questionnaire (ICIQ-LUTSqol) one week prior to interview (See Appendix H). The ICIQ-LUTSqol is based on the Kings Health Questionnaire and evaluates the global effects of urinary incontinence on quality of life. It specifically assesses 20 areas including household tasks, job, physical activities, travel, social life, friends, relationships, sex life, family, depression, anxiety/nervousness, bad feeling about self, sleep/rest, tiredness, urinary

---


symptoms, embarrassment and overall impact on everyday life, culminating in a measure that in some way reflects the degree of impact on quality of life.

The rationale for using this was so that the women would be aware of the depth and breadth of the upcoming interview, to guide interview questioning, and corroborate the women’s narratives.

As there are no validated questionnaires for assessing the impact of pelvic surgical mesh complications specifically, permission was sought from the copyright holder Bristol Urological Institute to modify this questionnaire to substitute “mesh problem” for “urinary problem.”

The modified questionnaire was then shared on the Mesh Down Under Facebook page for women to provide comment on their understanding of the term “mesh problem”. Twelve women responded and it was evident that to these women the term “mesh problem” was interpreted as an umbrella term for their own specific symptoms, demonstrating that it was an appropriate tool with which to proceed.

For each domain the women rate the extent to which the domain is affected by their mesh problem using the rating scale not at all, slightly, moderately, or a lot which are scored 1 through 4 respectively. They also rate the degree of “bother” out of 10 indicating the impact of individual symptoms for the person, but these scores are not incorporated into the overall score. A high overall score (range 19-76) indicates the level of impact on quality of life as defined by the ICIQ-LUTSqol.

In addition a further separate global spiritual question (Appendix I) adapted from the HOPE tool was asked of the women, “For some people, their religious or spiritual beliefs act as a source of comfort and strength in dealing with life’s ups and downs; what has been your experience?” They were then encouraged to rate their experience out of 10 using a similar scale to the bother scales on the ICIQ-LUTSqol, with zero equal to ‘has not helped at all’ and 10 equal to ‘has helped a great deal.’

Interviews

Interviews provided access to the women’s consciousness of their lived experience. In telling their stories, the women had the power to define their own bodies, identities and experience, rather than having their reality shaped by others. Their stories can be defined as illness narratives.

---

These narratives do not stand alone, and in health care, illness narratives sit within a ‘nest’ of broader background narratives influenced by society and culture, and grand or sacred narratives relating to religious or metaphysical belief systems which situate humans and human society within the cosmos.80

The women were interviewed once using a semi-structured approach (see interview schedule Appendix J), and asked to start their narratives with life before mesh. Interviews ranged from 45 minutes to 1.5 hours depending on the woman, to a point of natural closure.

Following this the interviews were transcribed verbatim and sent to the women via e-mail using password protected word documents to verify. Although this step is becoming less popular in qualitative research in terms of its contribution to validity, Charon says it is important to inhabit the stories of those who suffer, but to avoid colonising them.81 It was an intentional act of empowerment and balancing of power to return the transcripts to the women. This also kept lines of communication open, and led to ongoing exchanges by email.

Some women chose to make minor changes or add additional information to their transcripts, while others were happy to largely leave them as they were. The women were given two weeks to check and return transcripts.

The researcher was interviewer and transcriber, promoting increased familiarity with the women’s stories.

---

Data Analysis

The transcripts were analysed holistically and annotated as key words, phrases or themes emerged. Using selective reading as described by van Manen, the transcripts were analysed paragraph by paragraph, asking the question “What statement(s) or phrase(s) seem particularly essential or revealing about the experience of living with mesh complications?”

Each audio interview was listened to again to ensure that the essence of the experience of mesh complications as described by the woman had been accurately captured.

Van Manen’s four Lifeworld Existentials were used as a framework, and words/phrases and narrative blocks were sorted into themes and subthemes under the relevant existential. I aimed to use as much of the women’s verbatim narrative as possible. The women’s narrative is represented in indented *italics* throughout the Findings section.

---


Reliability and validity

Forister and Blessing says that in qualitative research a single experience or opinion can be meaningful, but this is enhanced when that single experience can be verified.\(^{84}\) Cresswell and Poth outline several strategies for validation of qualitative research, and suggest that a minimum of two should be used.\(^{85}\)

(Diagram from Cresswell and Poth, 2018, p260. Validation strategies used in this research marked with a star).

I have used between-method triangulation using data triangulation and methodological triangulation.\(^{86}\) The research data has been triangulated with two other points; the Australian Senate Inquiry report into surgical mesh,\(^{87}\) and the ICIQ questionnaire responses.

An authentic work gives participants freedom to speak, to have their voices heard and their perceptions accurately represented. The use of significant portions of the women’s

---

\(^{84}\) J. Glenn Forister and J. Dennis Blessing, eds., *Introduction to Research and Medical Literature for Health Professionals*, Fourth edition (Burlington, MA: Jones & Bartlett Learning, 2016), 107.


\(^{86}\) Immy Holloway and Kathleen Galvin, *Qualitative Research in Nursing and Healthcare*, 4th edition (Chichester, West Sussex, UK; Ames, Iowa: John Wiley & Sons Inc, 2017), 314. Triangulation is where the findings of one type of method are checked out by reference to another. Between-method triangulation involves using both quantitative (questionnaire) and qualitative (narrative) findings in this case.

\(^{87}\) Siewert, *Number of Women in Australia Who Have Had Transvaginal Mesh Implants and Related Matters.*
narratives allows the reader to accurately judge credibility and integrity and provides rich descriptions.

Themes (as per the diagram in the Findings section) were emailed to the women with a request to comment on whether they felt that the themes and sub-themes identified in the data analysis accurately reflected the essence of their experience. All seven women responded in the affirmative.

These things, along with identifying myself a complete member researcher, engaging in reflexivity, and extended immersion in the data over a period of ten months has allowed me to become sensitive to the nuances of each transcript.
Findings

The results from the ICIQ-LUTSqol questionnaire which the women completed one week prior to interview showed significant adverse impact on quality of life globally across the twenty areas assessed. A high overall score (scores can range from 19-76) indicates the level of impact on quality of life. The women’s scores ranged from 43 to 76, with the median being 63.

<table>
<thead>
<tr>
<th>Participant</th>
<th>Lisa</th>
<th>Julie</th>
<th>Ruth</th>
<th>Beth</th>
<th>Gloria</th>
<th>Penny</th>
<th>Donna</th>
</tr>
</thead>
<tbody>
<tr>
<td>Score</td>
<td>68</td>
<td>64</td>
<td>76</td>
<td>60</td>
<td>63</td>
<td>43</td>
<td>62</td>
</tr>
</tbody>
</table>

The areas that the women identified as impacted “a lot” prior to the interviews from highest to lowest degree of impact were:

- Family life, Job, and Normal activities outside of the home
- Household tasks, Physical activities, Ability to travel, Limits social life, Sex life
- Limited ability to see/visit friends, Wearing pads to keep dry
- Affects sleep, Worn out/tired, Change underclothes when they get wet, Get embarrassed, Relationship with Partner
- Anxious or Nervous, Careful how much fluid you drink, Worry in case you smell
- Feel depressed, Feel bad about yourself

The women rated how much mesh symptoms interfered with their everyday life, with zero being “not at all” and ten being “a great deal.” The majority of the women rated them as interfering a great deal. Only Penny indicated a moderate degree of interference.

<table>
<thead>
<tr>
<th>Participant</th>
<th>Lisa</th>
<th>Julie</th>
<th>Ruth</th>
<th>Beth</th>
<th>Gloria</th>
<th>Penny</th>
<th>Donna</th>
</tr>
</thead>
<tbody>
<tr>
<td>Score</td>
<td>10</td>
<td>9</td>
<td>10</td>
<td>10</td>
<td>10</td>
<td>5</td>
<td>10</td>
</tr>
</tbody>
</table>

Results from the additional spiritual question, scored in the same way, were that two of the women rated their religious and spiritual beliefs as a source of comfort and strength as a ten, having helped a great deal. The four highest scoring responses were from women who identified as Christians or who had church backgrounds. One woman rated her experience as a zero, indicating that religious and spiritual beliefs had not helped at all. The median score was five.

<table>
<thead>
<tr>
<th>Participant</th>
<th>Lisa</th>
<th>Julie</th>
<th>Ruth</th>
<th>Beth</th>
<th>Gloria</th>
<th>Penny</th>
<th>Donna</th>
</tr>
</thead>
<tbody>
<tr>
<td>Score</td>
<td>1</td>
<td>5</td>
<td>5</td>
<td>10</td>
<td>10</td>
<td>0</td>
<td>3</td>
</tr>
</tbody>
</table>
After analysing the women’s narratives, seven themes and corresponding subthemes were identified. These are represented below.

The themes correlate to some of the domains that women identified as highly impacted in the ICIQ-LUTSqol questionnaire, these being family life, job, normal activities outside the home, social life, and sex life. They also reflect wider concerns and impacts not assessed in the ICIQ-LUTSqol such as their experience of the medical space, pain, present and anticipated future losses, and the taboos around speaking about the genital area of their bodies.

Considering the work of Dunn et al in terms of recovery trajectories the women fit almost equally into the Cascading Health Problems and Settling for a New Normal categories.

Dunn et al., “Changed Women.”
As the women’s narratives unfold within each existential, the reader will be able to form a view as to why these trajectory categories were relevant at the time of interview.

**Lived Space (Spatiality)**

Lived space is an existential category for looking at the ways we experience our day to day existence. Women with mesh complications out of necessity spend much of their time seeking assistance for every day symptoms in the medical space, where they often feel powerless in this unfamiliar territory, and where the doctor and other health professionals are committed to inducting them into the lifeworld of healthcare.

**I knew something was wrong but the surgeon said the surgery was not the cause**

The Medical Practitioner: Patient Relationship

Engelhardt describes the interchange between health professionals and patients as defined by the language of healthcare, with symptoms translated into the special jargon of the healthcare professions. I note that the women’s narratives use much of this jargon, as they have become lay experts on their mesh complications.

The Australian Senate Inquiry highlighted that women had trusted the judgement of their medical practitioners, and yet had poor responses from them when they presented with complications. This was partly due to a lack of knowledge on the part of practitioners.

Greenberg says good medical practitioner: patient relationships rely on the practitioner’s expertise, but also on trust, trust that the practitioner cares about the patient’s wellbeing, and that the patient is seen as an individual with unique needs.

---


Todres et al.’s\textsuperscript{92} conceptual framework is mirrored what Cohn\textsuperscript{93} calls a “Buberian\textsuperscript{94} continuum of human relationships” in relation to the medical practitioner: patient relationship:

\begin{center}
\begin{tabular}{c|c|c|c|c|c}

<table>
<thead>
<tr>
<th>Humanising</th>
<th>Dehumanising</th>
</tr>
</thead>
<tbody>
<tr>
<td>\textbf{THOU}</td>
<td>\textbf{Medical Practitioner}</td>
</tr>
<tr>
<td>\textbf{Therapeutic}</td>
<td>\textbf{Medical}</td>
</tr>
<tr>
<td>\textbf{Subject}</td>
<td>\textbf{Medical Practitioner}</td>
</tr>
</tbody>
</table>

(Diagram adapted from Cohn, 2001)\textsuperscript{95}
\end{tabular}
\end{center}

She sees the relationship as a continuum with the medical practitioner: patient relationship moving between the two poles Thou, and It, and concurs that there are times, for example, such as in acute illness, surgery, or a medical emergency where an “I-It” approach characterised by abstraction, causality, detachment and utility is necessary.

However in chronic illness emphasis an “I-Thou” therapeutic relationship characterised by mutuality, acceptance and confirmation of otherness or uniqueness, wholeness and inclusion is needed.

Gloria’s experience with her surgeon pre-operatively speaks to issues around informed consent, the power imbalance inherent in medical practitioner: patient relationships, and demonstrates an I-It focus,

\begin{quote}
Right before the operation \ldots he actually suggested, well he kept asking me three times he asked, “Do you have leakage?” and I said “No, no”. “Does your bladder leak?” and I said, “No it doesn’t,” and he said, and he put it in three different ways. He says “Sometimes if you’re doing something active does it dribble?” I said “No, no” and he was getting a bit exasperated and he said again, “Does it ever, you know, a little bit of urine come out?” and I said, “Well maybe if I jumped on a trampoline or something.” And I realised he might not do the operation if I didn’t answer yes, and I realised he wanted the answer yes. What I didn’t know was that was another piece of TVT mesh going in. It was a separate piece from the pelvic floor mesh and that’s the one that’s caused the problem.
\end{quote}

Beth asked questions of her surgeon, and was given assurances,

\begin{flushright}
\textsuperscript{91} Tamara McClintock Greenberg, \textit{The Psychological Impact of Acute and Chronic Illness: A Practical Guide for Primary Care Physicians} (New York, NY: Springer, 2007), 125.
\textsuperscript{92} Todres, Galvin, and Holloway, “The Humanization of Healthcare.”
\textsuperscript{94} Originating from the work of Martin Buber.
\textsuperscript{95} Cohn, “Existential Medicine.”
\end{flushright}
He basically implied that this surgery was the best option that, and said that the mesh was inert, had been well researched, didn’t have any problems with shrinkage and things, that there had been long term studies done.

Donna looks back to her implant surgeries and asks,

“Why did I ever go with that?” but he was kind of so plausible and “I’ve had lots of experience I can fix this, it’s easy,” so I went with it and that was the start of the problems really.

I didn’t need all of that surgery, I didn’t, probably didn’t need the mesh put in, there was other alternatives that he never even offered me. So that is irritating, you know you put your trust in these surgeons, and yeah.”

Even as the surgeons appeared to be offering the women a choice, research shows they often do this through asking leading questions and rephrasing responses to confirm what they think is the right thing to do. The lack of two-way communication and accurate information has left the women living a journey that they would not have chosen had they been presented with all the relevant information and options.

Women present to medical practitioners because of the impact of mesh complications on their lived bodies but find the focus is on their pelvis, the personhood of the woman to whom that pelvis belongs is neglected. Conversely, when a woman is not understood as a person in context and relationship, the medical practitioner has less respect for her body.

This is evident in Beth’s narrative,

He (Gynaecologist) believed the surgery was a great success but the impact it had on my life was devastating and still continues to have far reaching effects. I knew something was wrong but the surgeon said the surgery was not the cause.

The gynaecologist has achieved anatomical success, restoring body parts to their usual position, but Beth’s lived experience of this is quite different. Research shows this is not unusual in pelvic surgery. Her own bodily intuition tells her something is wrong, but this is denied by the gynaecologist.

This sort of denial evidences not being able to take seriously any suffering that cannot be directly related to an anatomic or pathophysiologic disorder. The denial of lived experience makes it difficult to make sense of the experience, as what one is experiencing seems to be

97 Beth’s personal supporting documentation for a Health and Disability Commission complaint.
contrary to what the medical expert says one is permitted to experience. This ultimately impacts negatively on the medical practitioner: patient relationship.

Connolly explains why this is so,

“When a woman – or anyone - in a clinical encounter is placed in a situation of having to deny and distrust her felt sense of her own embodiment, then there is no ground for lived relation. When the lived body has no validity, then the object body becomes the viable site for commodity exchange within ostensible and paradoxical health “care” contexts. From there, it is a short distance to the abject and eventually, absent body, a body which one can manage, ignore and forget.”

As in Beth’s narrative previously, the surgeon has done his part and now the living with it is up to Beth, it is no longer his concern. He moves onto the next surgery, the next “cystocele repair” or “hysterectomy” on his list.

Donna tells of a discussion with her gynaecologist where she is reduced to her component parts; in this case her vagina,

I was only really getting minor leaking but I had a dragging feeling which probably was the pudendal nerve but he said, “Oh you’ve got a cystocele now, so we’ll do that and you’ve got a bit of leaking so we can put a sling in,” and then he said, “Then you’ll have a mega-vagina!” and I thought, “Oh great,” (sarcastic tone, laughs) because I’d have mesh back, front, top you know...

Many of the women had experienced this strange duality of experiencing themselves as subject, but being talked about as object by some of the medical practitioners who treated them.

When Donna started to experience complications the gynaecologist told her that she was the only one, engendering a sense of isolation, and bodily doubt,

(Gynaecologist) said I was the only one that had complications...I’m the rare case and stuff like that, what a load of...now I know it was, but at the time you know when it’s just you and then you sort of think, “Oh it’s just me.”

She explains that she doesn’t feel she is told the whole truth about the removal attempts, leaving her in a passive position where she is not provided with sufficient information to make decisions on her treatment. This raises issues of trust, and truth-telling,

---


101 Siewert, Number of Women in Australia Who Have Had Transvaginal Mesh Implants and Related Matters. Section 4.72 refers to women being told they were the only woman the surgeon had treated who had experienced complications, that they were an unusual case or that they were simply unlucky.
They would never tell me how much they got out... (Gynaecologist) would not look me in the eye and tell me how much they’d (Gynaecologist and Urologist) got out.

Later as Donna undergoes an ultrasound post-operatively to see if all the mesh has been removed, she is left struggling to make sense of what happens next,

He got one of his colleagues to do an ultrasound to see if all the mesh, that they had got all the mesh, he pointed to the screen, he said, “see all those little bits there? That’s all little bits of mesh,” …I thought “Oh well, they’ve told me they’ve got it all but those are little bits there.” Do you know he reported back to (Gynaecologist) that he could not identify any mesh. That still really upsets me. I did not do anything about that, I probably should have because it’s on my record, “No mesh could be identified.” He showed it to me! He pointed it out! ….So that’s like, it’s a bit of that old boys club, protecting each other.

Later Donna has further surgery with a different surgeon which shows that her interpretation of her bodily symptoms is correct,

…the posterior mesh…the one that was on the back wall had rolled up and one of the arms had broken off...so (surgeon) just keeps telling me, “We had to open your bladder like a book,” and what they discovered was when (previous surgeons), whoever closed up my bladder…had actually sewn mesh into the suture line of my bladder, oh and at the same time when (surgeons) took my, took it “all” she put a rectus – my own tissue – sling in, so that time I was cut hip to hip as well. So I had my own tissue but what (surgeon) found was she had left mesh, so there was my bladder then mesh, and then my own tissue sling, so it was an absolute nightmare for them to try and get that out without harming my own tissue sling. I’ve got a 15 cm arm that they took out from the sacrospinus ligament because I’d been having terrible tail bone pain, oh that was just terrible but I found out later it’s because of where they attach it, it just pulls on the tailbone...so (surgeon) and (surgeon) did not get all the mesh. They left, there was a lot left behind including this arm...I am left with, still got arms in the obturator area because they are too dangerous to get out.

For other women their sense of agency was affected when they realised that they had not been told the full story, or offered all the options. Ruth requested a copy of her notes, and found a letter that left her feeling betrayed,

(Gynaecologist)... sent a letter to my doctor saying I was a good candidate for mesh. Nobody told me this - that I was going to get mesh.

Once experiencing complications she got a second opinion from another gynaecologist,

He said everything was fine but he wrote to the doctor and said, “I could take this mesh out.” Now it had only been in six months, if I had known that, and that that
was causing the problems he could have taken it out right there and then, and I wouldn’t have had this sort of life...

This loss of personal journey as Ruth perceived she would have lived it, and not being given the opportunity to have chosen an option that may have improved her life has led to a grief borne of injustice, from the knowledge that her complications did not need to happen, and that they were ultimately preventable.

In Isom-Batz and Zimmern’s experience many women experiencing complications say they would rather have lived with some prolapse than the symptoms they now live with. Dunn et al. also refer to the regrets of women in their study, and how they would have chosen differently had they known the risks.

Postoperatively after her mesh implantation surgery Gloria was unable to pass urine so the surgeon put in a suprapubic catheter, no small thing, and the next day she was discharged with little explanation,

I was just expected to get on with it. It was actually daunting because I had never, I didn’t even really know much about supra- you know that you could do, I knew that some people sort of had bags and things, colostomies but I didn’t really, I hadn’t known anyone who’d experienced this. And I thought, “He was a good surgeon” you know, he was an ex (town) boy so he must be alright (laughs).

Years later, Gloria had a consultation with her urologist about the complications she was continuing to experience with her bladder having had the supra-pubic catheter removed and subsequently learned how to self-catheterise. She found that she was unable to make sense of what she was told,

He (Urologist) talked in medical terms and we were really struggling to keep up with what he was saying but I did remember quite a lot of what he said and wrote it down as soon as I got back, but it was almost as though he was trying to overwhelm us with, medical talk rather than listening to, you know, he had a patter that he used for people like me.

Julie had formerly worked in the medical space, so didn’t have this problem, but because of her experiences as a patient in this space had experienced intrapsychic losses; faith and trust,

I’m disappointed in a service and structure that I loved. And now I have no faith in. You know, you know sometimes when you’re so sore that you think, “Maybe I should

103 Dunn et al., “Changed Women.”
104 Catheter passed through abdominal wall into the bladder. Commonly used for long term catheterisation.
“go to the hospital?” And then I go well, they’re not gonna make anything better, they’re only gonna cock some more up, you know what I mean? Why would I go there?

After getting copies of her medical notes she was surprised to discover that she had not been given the full facts prior to a potentially life-threatening surgery,

In my medical notes it says that the multidisciplinary meeting suggested they excise this bit and see what’s going on but the risk for damage was rather large, which wasn’t what, the story I heard either...I was under the opinion that my life was at risk if I didn’t have the op. Which it might have been. They did say right on the femoral artery.

Having lost her agency in relation to her treatment, along with a post-operative recovery marred by a lack of health professional understanding that she was not a “routine” case, Julie hints at the hypervigilance required in that space throughout her wider narrative; the sense of having to keep an eye on everything that is done to her to prevent something bad from happening.

Similarly Ruth says,

It’s like at one time you would never question anything your doctor said or did you just, they know best, but now I’m fighting it for everything. I’m fighting because I don’t want the mesh cut, I’m fighting because I don’t want to be drugged up and become dependent on it...so now I question everything that they say to me and want to do.

But rather than avoiding the medical space, Ruth talks about “fighting” for what she wants, or doesn’t want in that space. She is determined to be passive no more, and make her wishes known. Toombs highlights that it is often difficult to reject medical advice as to do so we risk being isolated from the one who promises to alleviate our distress, but Ruth’s experiences have taught her that what medical practitioners recommend is not always in her best interests.

In contrast, Donna describes a moment of togetherness, and compassion with her surgeon prior to one of many surgeries to remove mesh,

That time (surgeon) was actually very genuine, he sat on my bed before the surgery and tapped my knee and he said, “I am so sorry,” and I thought, “Well that’s actually really lovely,” and accepted his apology. So mistakes happen and that’s the way it is.

However as Donna continues to have problems, and writes letters to both surgeons involved in her care and receives no response. She feels let down and upset by this.

When cure of their symptoms becomes impossible, many of the women find themselves abandoned, and experience isolation, a sense of dislocation, and that their journeys toward a mesh-free future are halted until they find someone else who can help. Dunn et al. also refer to this saying the women in their study drifted into hopelessness or became critical of surgeon’s inability or unwillingness to help them.\textsuperscript{106}

The expertise required to implant mesh is less than the higher level of surgical expertise required to remove it once nerves, blood vessels and tissue have grown through the weave of the mesh. Removal can cause further harm, as is evidenced in Lisa’s narrative in the following section.

All in your head

Conrad and Barker suggest that medically invisible conditions that cannot be readily associated with a discernible biomedical abnormality make it difficult for a person to have their symptoms acknowledged, and raise suspicions that the problems are “all in their heads.”\textsuperscript{107}

Donna tells of arriving at the conclusion it was all in her head after the urologist declined to do a further cystoscopy to check if her symptoms were related to mesh that had been left behind,

\begin{quote}
I said, “So what about another cystoscopy to check?” and she (Urologist) said, “Nope there is no need to do another cystoscopy. There is no way you will have any mesh in your bladder, we got it all out.” So basically she refused me treatment or investigation. And so after that I just, you know you get quite down and it’s like, “Oh well, maybe it’s all in my head,” and you know she’s telling me it’s nothing and just my brain remembering the pain so I just have to deal with it.\textsuperscript{108}
\end{quote}

As it turns out ‘dealing with it’ was easier said than done, and later in the Lived Other section we’ll see the impact of this perspective on Donna. Lisa was told a similar narrative, one that left her struggling intrapsychically to make sense of her bodily symptoms in the light of being told that there was no mesh left to cause such symptoms,

\textsuperscript{106} Dunn et al., “Changed Women,” 133.
\textsuperscript{108} This advice is based on chronic pain theory. Where chronic pain persists despite the removal of the original cause is called Persistent Central Sensitisation Pain, and reflects the nervous system ‘remembering’ the stimulation of a particular pain pathway.
Now that I know its mesh, but you know, I had a sore pelvis and couldn’t sit but supposedly had no mesh inside me, so everybody tells you it’s in your brain, and it’s like you fight with yourself, because...you’re in pain but there’s no reason, you know what I mean? Or you can’t sit, but it’s been removed. But it wasn’t removed and so now that I know I’ve got mesh...

Mesh is extremely difficult to detect radiologically, and the internal structures of the pelvis make it difficult to visualise to detect abnormality. The assumption is often made by medical practitioners, and sometimes the women, that if the problem cannot be found in the body it must be in the mind. The Australian Senate Inquiry found that this is had been the experience for many women.109

After coming to the conclusion that it must be all in her mind because she had been told that she was mesh free, yet experiencing bodily symptoms that suggested she wasn’t, Lisa underwent surgery which affirmed her bodily knowing,

I was full of mesh, completely (laughs). They had hacked a portion of the posterior mesh away and it’s where the bowel had come through. They hadn’t touched the anterior mesh at all and they hadn’t touched the sling which I didn’t even know.

Connolly reflects that historically women’s problems in particular were put down to hysteria, and to this day are often devalued, and interpreted as “psychological” or “emotional” in their etiology and dismissed as trivial.110 Studies show that this gender bias still exists with some health professionals believing that women are more likely to experience pain of psychogenic origins.111

The effect of being told ‘there is nothing wrong with you’ regardless of how incapacitated they are can completely undermine a woman’s confidence in their lived experience and relationship to reality.

Beth relates this at least in part to mesh complications not being a visible disability,

Unfortunately, in contrast to a broken leg, people can’t see what mesh does to you on the inside and the effect it has on your ability to function, but it’s a world of pain that ruins your life.

---

109 Siewert, Number of Women in Australia Who Have Had Transvaginal Mesh Implants and Related Matters, 78, Section 4.73.
110 Connolly, M, Female Embodiment in Clinical Practice in Toombs, Handbook of Phenomenology and Medicine, 189.
Charmaz says looking ‘healthy,’ and the invisibility of pain, can also undermine one’s credibility with health practitioners, and the same applies to others the women engage with regularly.

Getting support from the system

Charmaz says that where one ranks in the moral hierarchy of suffering affects the social response to one’s suffering. Social institutions, such as the Accident Compensation Corporation (ACC) respond with assistance to some categories of illness or injury while denying others or treating those suffering them with bureaucratic indifference. This leaves groups of marginalised people, such as women with mesh complications, fighting for a diagnosis.

Having a diagnosis of a condition resulting from treatment injury entitles a person to taxpayer funded treatment and support. In New Zealand this has proved problematic as medical practitioners must assign a diagnosis, and yet some have been reluctant to be accountable for their part in the treatment injury. This has left some of the women bearing the additional burden of proving their complications, and until they can, unable to access the support they need.

Several of the women had been through the ACC review process whereby their original claims for treatment injury, and thus access to funded treatment and rehabilitation had been declined. They then had to go through a review process to try and get the decision reversed. Lisa, Julie and Ruth underwent multiple reviews.

Lisa and Julie both talked of reviews conducted in a motel unit in their respective areas, with the ACC representative on a microphone. Both felt disrespected and their lived experience ignored. Julie said,

It was just a horrible process because I actually expected ACC to be there but they weren’t even there...they can stall you for this long, and take no notice of you but then they don’t even have the decency to show their face in the room.

114 This reluctance may be related to the inference of previous terminology for treatment injury up until 2005, “medical misadventure” and the associated connotations.
Having to share intimate details of their pelvic function and the impact on their lives with a faceless person at the end of a microphone engendered a sense of dislocation, passivity and powerlessness. Dumit calls this “symbolic domination.”

Julie had experienced role loss, and admits that her role as a health professional had been her identity. With ACC adamant that her symptoms were not related to mesh, she found herself doubting her professional knowledge and experience and her-self.

Ruth had a face-to-face hearing, and tells how her husband helped win her review with ACC,

*It [ACC document] said how three specialists who’d been seeing me had all said the mesh was too tight, and that had caused infections, and the two ACC doctors had said there’s nothing wrong with me. So (husband) said, “How come they can say that when they haven’t seen you and the three that have seen you have said that?”*

Ruth’s husband made this point at the Fairway hearing and the original decision to decline her claim was successfully overturned.

Lisa found herself somewhat powerless after having the second stage of a two-part operation cancelled by ACC, leaving her having to get a lawyer to have the surgery completed,

*I got the stimulator, but to get the stimulator I had the first operation where…and they leave all the wires out your back and they attach it to a computer unit that’s around your waist. ACC cancelled the second operation. Left with wires hanging out but no unit, had to get ACC lawyer involved so could proceed.*

Only one participant, Donna, had had a positive experience with ACC, saying that the support she has had makes her feel “guilty” that other women haven’t had their claims accepted.

In 2017 a report by the Otago University Faculty of Law, Legal Issues Centre highlighted the often obstructive and legalistic approach adopted by ACC to treatment injury claims.

---


116 FairWay is a dispute resolution provider, one of their workstreams is resolving ACC claim reviews. https://www.fairwayresolution.com/acc

117 Tibial Nerve Stimulation works by indirectly stimulating the nerves responsible for bladder and pelvic floor function. An electrode is implanted near the nerve and can both reduce neuropathic pain and improve bladder function.

118 Lisa, private document, timeline of her mesh journey.

119 W Forster, T Barraclough, and T Mijatov, “‘Solving the Problem: Causation, Transparency and Access to Justice in New Zealand’s Personal Injury System’” (Dunedin: Otago University Faculty of Law Legal Issues Centre, May 22, 2017), http://www.otago.ac.nz/legal-issues/otago651299.pdf. Geoffrey Palmer, former prime minister and QC used the 2018 Sir Owen Woodhouse Memorial Lecture at Victoria University this year as a platform to highlight flaws in the way the ACC system is implemented currently. He said that the current
It's like the problems caused by surgery devoured everything and left behind a complete wasteland

This powerful metaphor illustrates that alongside this sense of powerlessness in the medical space women experience a world that is shrinking, with the loss of personal and professional roles, social isolation (discussed in the Lived Other section), limited ability to travel, and limited financial resources. What once seemed like an expansive world of opportunity now feels contracted and is dependent on one’s body’s capacity to engage on any given day. This contracted life leads to fewer opportunities to re-construct a valued self.

Julie talks about the loss of her job and its impact on her material world. In the same piece of narrative (not quoted) she talked about previously being able to afford glasses, dental work and mechanical work on her car. However the loss of her job means that she doesn’t have the financial capability to do anything other than survive week to week,

I was never in a high paying job, so now I don’t have Kiwisaver cos ACC doesn’t pay Kiwisaver, um I had contracts that I was floating with, um I’ve just lost the last one, and that was a little soul destroying. That took me a week to recover from...I’m scared, I’m scared of my future, because I’ve got a mortgage to pay off...The moment you turn sixty five ACC dumps you and you’re on a pension. So I have to have my mortgage paid off by sixty five. So I am going to have to get flatmates. Yay (flat voice). You know it’s kind of like it’s hard enough to adjust to this little place anyway, and now I’m looking at flatmates? Just so that I might be able to have a cup of coffee when I turn sixty five...So there’s quite a lot of financial pressure.

Dunn et al. also refer to the depletion of emotional and practical resources amongst the women in their study.¹²⁰ The Australian Senate inquiry findings support this also, with women sharing that the limitations due to symptoms have impacted their ability to work, and that while some could modify their working arrangements, others found that they were no longer able to work, creating financial stress for them and their families.¹²¹

Donna describes the role loss she experienced, and still grieves, along with the intrapsychic conflict she experienced in having to leave her job due to the impact of mesh complications and related surgeries,
The plan was after that surgery I was going back to work. But as time went on I got to the six week mark and there was no way I could, was ready to go back to work. Got to eight weeks, still no way...I think I even got to the three month point and I thought...and I was so upset because I loved my job. And then we started talking about early retirement on medical grounds and that was the most difficult thing I've ever had to do. It still took me over a month to actually make that decision because that was a very hard decision to make. And so I decided it was best for everyone, because I was feeling guilty that I was letting work down, medical teams were telling me no you shouldn’t be working, I was trying to tell myself, “I can work, I love my job, I want to go back to my work,” so I was having this continual sort of battle, then I ended up, yup I think everyone is right I just have to.

Aside from the financial burden of not being able to work, there are benefits in terms of not having to battle physically and psychologically to function in a work role while coping with mesh complications, as Lisa describes,

If anything now it’s like I say to my psychologist, “I’m in a better mental state now than I have been for years,” and it’s that pressure of not having to work, to actually be told, “you can’t work,” and now my goal is to build up my strength so that I can stand and I can do stuff and do more stuff, and go to (volunteer work) twice a week, doing what you can for others.

Julie talked about how much her physical world had shrunk to within a 10 minute radius of home and the impact of this on her quality of life and strength for life,

I think that’s one of the things I miss the most, is being able to go anywhere...I can’t do anything under my own steam and if I do go to town I can do one or two things and I have to turn around and come back. I can’t, I can’t achieve very much...once upon a time you had a list and you could knock it all off in an hour (laughs), now my lists, if I’ve got a list of stuff I’m, it takes me forever to make it through a list, you know, it’s like “Okay, I can do this today,” and then I might not achieve anything in a week.

My mobility is probably what upsets me the most, the fact that I just can’t get anywhere...being mobile would make a huge difference to me cos then I wouldn’t feel like I wasn’t living a life.

The limitations Julie experiences as a result of mesh complications change the landscape of her world, and the life she lives in that world.

Travel has to be planned, energy rationed, and pain burden managed, the women’s bodies determine what can be done, when, for how long, and in what way.
Medical Trauma

Two women, Julie and Donna, have diagnosed Post Traumatic Stress related to trauma experienced in this space, and some of the other women have also experienced significant undiagnosed trauma related to their accumulated adversity.

Donna describes a panic attack she experienced when visiting the hospital where she had a 17 hour surgery for mesh complications. When walking past the Intensive Care Unit where she spent several days post operatively and had wanted to die, she experienced the following symptoms,

I came over feeling really ill and my heart started pounding and I thought, “Oh what’s going on?” and I couldn’t work it out. So then I just did some deep breathing and, felt really shakey...It was like an anxiety kind of, cos I thought, “This is not me, I don’t do this sort of thing,” you know and I’d never experienced it before, and it was the same watching medical things that it just obviously triggered some sort of post-traumatic thing that was...so that was really hard to deal with. That was probably a year that I was suffering badly with that.

Tedstone and Tarrier explain that PTSD can develop as the result of prolonged or unpleasant medical and surgical procedures and treatment leading to high levels of fear, anxiety about the future and feelings of helplessness and loss of control.122

Julie, who had complex surgery to remove mesh which was sitting on her femoral artery, relates her diagnosed PTSD to hospitals and ACC saying,

I hate both of them, I start shaking at ACC and, of course they make you go there.

For both Donna and Julie each new encounter in the medical space is contaminated by past trauma experienced there. Hall and Hall describe this as “medical trauma” that occurs from direct contact with the medical space, and develops through a complex interaction between themselves as patients, medical staff, the medical environment and diagnostic or procedural experiences.123

Hall and Hall’s Ecological model of medical trauma:124

123 Hall and Hall, *Managing the Psychological Impact of Medical Trauma*, 19.
124 Hall and Hall, 32.
For women with mesh complications their trauma begins with what has been done to the body.

**Lived Body (Corporeal)**

We are always bodily in the world, however mesh complications, cause a loss of wholeness, and a concurrent disruption of the women’s being-in-the-world. The body can no longer be taken for granted. The impact of mesh complications on how women experience life through their bodies fundamentally disrupts the unity between their bodies, and their selves. When the body breaks down what happens, happens not just to the body but also to the life that is lived in that body, says Frank.125

The women live with **unrelenting pain and discomfort**, inhabiting a body that cannot be **relied on**, especially as it relates to bowel and bladder function, ability to sleep, function as a sexual being, sit, walk or stand for any length of time. They have good days and bad days in terms of pain, fatigue and a multitude of other symptoms, and this determines how they function bodily in the world. The primary loss in this existential is functional loss, which is experienced as a loss of wholeness, of bodily integrity.

---

Rather than functioning effectively at the direction of the self, the body-in-pain, or the body-malfunctioning thwarts plans, impedes choices, and renders one’s usual actions impossible.

Coping with chronic illness requires routinely scanning minute bodily processes, and there is a daily quest for control of known catalysts or triggers, especially those that provoke pain. Pain in particular brings mesh complications to the forefront of bodily awareness, and is a constant reminder of the women’s powerlessness in relation to the ever-present, yet unseen mesh, the foreign body within their bodies, and the cause of their suffering, their “thorn in the flesh.”

I am not sure how much more my body and spirit can take

The women could remember their implanting surgery, and subsequent surgeries to attempt to resolve complications, vividly. One woman was about to undergo her sixteenth surgery (including two implant surgeries). Handing over one’s body to a surgeon, to work in the inner spaces of one’s body in the hope of some improvement in function, with a potentially uncertain outcome, knowing that you will have weeks if not months of recovery ahead of you takes courage.

Penny had to have three further surgeries to manage complications from her implant surgery.

Julie faced a potentially life-threatening surgery to remove mesh which was lying against her femoral artery. In this piece of narrative she talks about how the surgeon’s third person description of the state of her vagina prompted her to undertake the surgery,

This side (indicating right) was sitting in, on my femoral artery…on my femoral artery for God’s sake…she (Gynaecologist) said my vagina was just all granuloma tissue in there, she said, “It’s a mess”…she said, “You can’t actually function with this mess of granuloma tissue that you’ve got going on here.” So I did my will, redid my will and ended up in theatre two years ago...

Likewise Donna had difficult decisions to make in relation to surgery, with uncertain outcomes.

He’s (Urologist) really worried because my bladder’s been cut into so many times and the position of the mesh it’s so close to the ureter he actually thinks he’s gonna have to cut the ureter off and reattach it.

---

126 In the literal sense, similar to the apostle Paul’s description of a “thorn in the flesh” (2 Cor 12:7-10), some women describing it as feeling like barbed wire.

127 To remove a granulation abscess and manage mesh erosion.
And Lisa, who had been unable to walk prior to a long surgery to correct complications, weighed the risks and benefits of further surgery,

There’s so much scar tissue down there and there’s so much nerves that are mucked up and that. I’ve got something like a 20% chance that I will still be able to walk, and you know it’s gotta be a positive outcome, so 80% negative outcome...those aren’t good statistics.

Pain

The Australian Senate report found that a recurring theme across the accounts they received was that of chronic and debilitating pain that impacts every aspect of women’s lives. Bendelow and Williams say that pain is simultaneously both physical and emotional, biological and phenomenologically embodied. Leder affirms this saying that it reorganises lived space and time, relations with others and the self.

Many women never experience resolution of their pain. Beth and Donna woke from their surgeries in severe pain, and have not been free from pain since,

When it came to the day of surgery, when I woke up immediately everything was a disaster. The pain just hit, I couldn’t sit, stand or walk for more than five minutes without feeling the need to lie down. The pain in my lower back, pelvic and bladder was severe and everything was inflamed underneath. I knew something was wrong but the surgeon said the surgery was not the cause...When I was discharged I was still in the same amount of pain.

Rather than acknowledging Beth’s sense that something is wrong, and removing the implant Beth is sent home in severe pain. Donna had a similar experience, and spent several years having her back investigated as a potential cause of the pain,

Immediately after the surgery I had terrible buttock pain and started to get leg pain, and he, because I had some bleeding, he sent me to (General surgeon), which ended up that there was some haemorrhoids, and (General surgeon) did, you know, sorted that bit out but he thought, and even wrote back to (Gynaecologist) that he thought the buttock pain and the leg pain may be related to the mesh...but (Gynaecologist) said “No, no, no it can’t be anything to do with that,” so nothing happened.

128 Siewert, Number of Women in Australia Who Have Had Transvaginal Mesh Implants and Related Matters, Section 2.12.
130 Leder, The Absent Body, 73.
Donna’s perspective is outweighed by the surgeon’s perspective, he will not ‘authorise’ her explanation for the pain.

Wendell explains the impact of invalidation of symptoms such as pain,

The cognitive and social authority of medicine includes the power to confirm or deny the reality of everyone’s bodily experience. Thus medicine can undermine our belief in ourselves as knowers, since it can cast authoritative doubt on some of our most powerful, immediate experiences, unless they are confirmed by authorised medical descriptions, usually based on scientific laboratory results. Moreover this power of medicine also subjects us to possible private and public invalidation by others – invalidation as knowers and as truth tellers.

Patients with chronic disabilities have expert knowledge of what is ‘normal’ and ‘abnormal’ in relation to their own bodily experience. As Donna later wrote in a letter to one of the surgeons who had done her initial mesh removal surgery,

I believe most patients know their bodies and that just because a patient doesn’t make a big fuss about their pain they should still be listened to and taken seriously.

For others the pain started later, and has a huge impact on their day to day functioning, with simple things such as sitting, traveling in a car or going to the toilet becoming difficult.

Donna suffers chronic pain on top of the acute post-surgical pain, as her bladder fills the pain increases, and similarly on emptying her bladder this is also painful. Our bladders fill and empty multiple times throughout the day, so this pain is unrelenting,

Since 2010 I have not been able to urinate without terrible pain...the pain makes me very nauseated...so any movement, any bending just then I come over, “Oh I feel so sick,” and then every time I go to the toilet I come out and it’s like “Ohh.”

Bowel movements are something our bodies produce every day. Beth describes her daily experience prior to mesh removal,

Before the mesh was removed when I had a bowel movement it was very painful. As it moved down into the rectum past the point where it went over the mesh it caused so much pain. Oh I can remember it. It was like a terrible pulling, cramping pain in the lower pelvic, bladder area, like something was going to tear.

She explains that,

Being sore most of the time is tiring, I often don’t feel well and it gets me down sometimes. I think just being sore most of the time is tiring. It’s hard because doing

---

132 Donna, private letter to surgeon dated 14 October 2015.
stuff when you’re sore is more draining. I think it’s just the stress of coping with things overall which becomes tiring, trying to make decisions, wondering what to do next, yeah it can become emotionally taxing…

Julie talks about what it is like to get severe pain in an especially sensitive area of the body, her symptoms related to nerve damage,

*It feels like there’s a chili up my vagina, I get stabbing through my clitoris. That’s not much fun. You’re not supposed to know your clitoris is there unless it’s having a ball…the cramping in the groin and the stabbing in the clitoris are random…unless if I walk too far that’ll set that off…it’s not too good when you are driving.*

Penny highlights the difficulty of being able to locate the pain, or describe it to others, especially medical practitioners,

*In my bowel it just feels like there’s a stick up your bum (laughs), yup. The side of my, I assume it’s my vagina, it just aches. I’m not very good at describing it, even to the doctors, you know. “Describe your pain.” “Well it’s on the right side,” then they put their fingers in and go to the left side and, “Oh that really hurts!”*

Lisa had a fall while skiing, hurting her knee, which led to severe consequences in her pelvis which she puts down to a “whiplash effect,” where as she fell the impact sheared nerves and capillaries that had grown through the mesh. Afterwards she wasn’t able to walk,

*And so I got sent to (tertiary hospital) and they were so shocked because my whole pelvis was in spasm. The pain was horrendous. I can see that if you fall, are in an accident or something, when you’ve got mesh in your pelvis you are never ever safe.*

*It’s taken me a lot to admit I’m in pain. I’d say I have spasms or an electric shock go down my leg or I can’t sit and how I explain sitting is like how if you sit on a stone or a pea…it just gets harder and harder and it turns into a boulder until you’ve got this massive pulse in your pelvis that you just can’t sit anymore, but I never used to say I had pain.*

She was later diagnosed with type 2 Chronic Regional Pain Syndrome in her pelvis and piriformis syndrome.\(^\text{133}\)

---

\(\text{133} \) Piriformis syndrome is a condition in which the piriformis muscle, located in the buttock region, spasms and causes buttock pain. The piriformis muscle can also irritate the nearby sciatic nerve and cause pain, numbness and tingling along the back of the leg and into the foot (similar to sciatic pain). Chronic Mesh Pain Syndrome, a complex pain condition that develops post mesh surgery with pain persisting past the post-operative period (>90 days) is also beginning to be recognised. This pain is not necessarily reversible with mesh removal. Chronic Pelvic Pain Syndrome is another term used for pain in this area.
Erosion

Erosion is a complication specific to mesh, and is often talked about in the literature as a “minor” complication easily fixed in the clinic. This was addressed by the Australian Senate Inquiry who said “The committee understands that for some women the experience of mesh exposure or erosion is far from a minor complication and can be painful and distressing, requiring multiple surgeries.” This was also the case for the women in my study.

Penny describes the pain and shame she experienced with mesh erosion,

It stings, it aches, the discharge. I don’t remember smell. I didn’t want my husband touching me or anything, you know I didn’t, I felt um embarrassed but no-one knew that I was embarrassed about it. Really, really embarrassed...I only worked it out with the discharge when I got my hospital notes...and I thought, “So that was all that muck,” so yeah, really really embarrassed.

Lisa likened her pain to having a saw in her vagina,

It’s like a saw. Every step you take hurts. You’ve got something inside you, it’s like a saw and every step you take whenever you walk hurts...

Donna has experienced multiple occasions of erosion, and uses the metaphor of barbed wire,

It’s eroded into my bladder, four, five times...Um, it felt like when I was walking it would feel like I had barbed wire in me rubbing, so that was very uncomfortable...

While from the medical practitioner’s perspective trimming the mesh in the clinic may be easily fixed, it is clear that the lived experience of mesh erosion is far from minor and has a huge impact on day to day living, bringing awareness of the dys-appearing body to the forefront of every moment.

Julie told her gynaecologist that she could feel sharp things in her vagina and was told by the gynaecologist that they were deep seated muscle sutures that hadn’t dissolved and were coming through into the vagina,

---

135 Siewert, Number of Women in Australia Who Have Had Transvaginal Mesh Implants and Related Matters, Section 2.28.
And in the rooms at the hospital she was snipping them with scissors up my vagina, which is quite scary cos you’re trying to pull your vagina back because you just kind of want to go backwards when someone’s got at scissors at you.

Interestingly none of the women talked about the experience of having to be examined in vulnerable positions, or of intrusions into orifices, perhaps because this had become so routine and was viewed as a means to an end, to provide answers and symptom relief.

Sleep

Sleep is important for coping and mood when one is experiencing physical and psychological stress. Straube and Heesen point out that lack of sleep can decrease pain tolerance, increase fatigue and have functional consequences in people with painful conditions.137 Sleeping was a problem for five out of the seven women who struggled to sleep due to pain and discomfort. It was rated in the mid-range of impacts in the ICIQ-LUTSqol but the women’s narratives suggest it may have a more significant impact.

Gloria, Donna and Lisa describe their struggles with getting into a comfortable position, and being limited as to what position they can sleep in.

Donna in particular finds the nights long, often sleeping in a lazy boy chair in the lounge so as not to disturb her husband,

I don’t sleep very well because I can’t really lie on my side, and if I do get onto my side and then the bladder pain starts and then I’ve got to roll over, and then the leg, groin starts burning…Sleep hasn’t been good for years…It would at a maximum be three hours before I am awake and needing to do, you know reposition or breathe through the pain, and then I’ll get another few hours…I feel terrible because I am disturbing (husband) so sometimes it’s better to come out here (lounge) um cos he’s gotta keep working but every time I’m trying to get into a better position it’s disturbing him…Often I come out and I recline that chair right back and sleep out there, sort of plug into my music, some relaxing music, lie on that chair, feet up and kind of doze off and then I try, some nights I am there all night, otherwise I try and get back into bed, and so sleep is terrible. Sleep hasn’t been good for years.

136 As highlighted in the work of Luna Dolezal with women undergoing gynaecological procedures in, “The Phenomenology of Shame in the Clinical Encounter,” Medicine, Health Care and Philosophy 18, no. 4 (November 2015): 573, 4, https://doi.org/10.1007/s11019-015-9654-5. Women with mesh complications are routinely examined both vaginally and rectally.

Lisa has her own way of managing it, rather than avoiding lying on the sore side, she lies on it until she passes out with the pain or goes to sleep,

_This may sound really stupid but when it’s really sore I lie on it til it goes numb til I pass out basically...eventually you go to sleep or whatever..._

For Ruth, it’s being woken by the pain, and a busy mind, the uncertainty of her own situation and her concern for others worse off, especially younger women,

_Even I can be asleep and suddenly I’m wide awake with the thoughts going round in my head about mesh, or the pain’ll wake me._

Sexual intimacy

The Australian senate inquiry was told that the loss of ability to sustain an intimate relationship caused women emotional grief and pain. Loss of sexual function, for those who were sexually active was a profound loss. Loss of sexual intimacy, or the ability to have sex was talked about by all the women in my research.

Research shows that dyspareunia, difficult or painful sex is common, and similarly, “hispareunia,” a term coined specifically in relation to male partners. This is where contact with eroded mesh in the vagina can lead to laceration of the penis. Lisa and her husband experienced this prior to their marriage break up,

---

138 Siewert, _Number of Women in Australia Who Have Had Transvaginal Mesh Implants and Related Matters_, 27, Section 2.61.
Near the end of the year when my husband and I were trying to be intimate he got cut by mesh and there was just blood everywhere...

Most often the limiting factor in intimate relationships is the pain experienced by the woman. In the ICIQ-LUTSqol the impact on sex life was rated higher than the impact on their relationships with their partner. They wanted to have sex, and some acknowledged their inability to meet their partner’s sexual needs.

Penny says,

Sex life is completely nil cos that’s too painful and I’ve got so much scarring in my vagina that it’s, it’s not good. Yeah when he did when I had the mesh, he could feel it, yeah, but he didn’t get injured, but he, it was not good so we, our sex life has not been good.

Gloria shares how uncomfortable sex is for her,

It sorts of cuts when we do have penetrative sex, which we don’t do much now...we find other ways to pleasure each other...we don’t want to lose it too soon.

Donna provides insight into her husband’s experience,

It’s very, just about non-existent, and that’s why I am so lucky with (husband), he’s so tolerant and he gets anxious because he doesn’t want to hurt me...

Mesh complications impact on non-sexual intimacy as well, as Penny describes,

It’s annoying, it’s really annoying at night when you’re tired, you’re just talking to your husband and you think, “Oh it’d be nice to just have a cuddle,” and then you think, “Oh actually I’m too tired and I hurt too much.”

Beth shares that she doesn’t even know if sex is possible, and this functional loss has led to anticipated relational loss,

If I were to ever try and have an intimate relationship with someone I would need to use lignocaine gel or something, even then I don’t know if it would be possible. Given this, I thought it was best to not go down that road as I often think what guy would want to know me if they knew?...I have had people react like I am some kind of freak when they hear I am single and never had sex, it’s like you’re (age) how could you still be a virgin? They don’t stop and consider there could be a valid reason.

When Beth’s mesh was removed it was found to be wrapped around her uterus, and she had to undergo a hysterectomy, so even if she were able to have sexual intercourse she no longer has the ability to have children. She did not refer to this loss specifically in her narrative.
Unfortunately for some women, like Lisa, who have had multiple pelvic surgeries the nerve damage sustained means that there is no sensation in the genital area, and vaginal length is insufficient to have penetrative sex,

  It just doesn’t exist. I mean basically nothing down there works...they didn’t have enough tissue to form a vagina...it’s short but there’s still, but there’s virtually no feeling down there.

Julie who talked about her satisfying sex life before mesh, has had to face the knowledge that she will never have sex again because of the damage to her vagina (which took seven months to heal/close after the surgery due to a lack of tissue available to close it surgically), and pelvis, making intercourse not only physically impossible, but any internal or external contact with the pelvic or abdominal areas causes pain.

All of the things I could do are off the table now

The women rated the impact on activities outside the home highly, along with limitations on their social lives (discussed in Lived Other) and household and physical activities as being impacted significantly in their responses to the ICIQ-LUTSqol questionnaire.

Many of the women’s pre-mesh activities are “off the table now” and there is a price to pay for any activity, usually in the form of increased pain during or afterwards.

As Lisa explains,

  If I plan to do something I will complete it but if I have to stay in bed for a week as a result...if I swim and I have to spend the whole day in bed, I’ve done something, it’s better than nothing.

Donna refers to not having been able to do “anything” over the last few years. Julie lives a sedentary life compared to what she was capable of in her before-mesh life for similar reasons, avoiding pain, and living day to day within her body’s limitations.

Gloria, in a later piece of narrative refers to feeling like she doesn’t have much to offer, and feels powerless to meet the needs that she sees in her community. She describes feeling bodily like an older lady, when inside she is the same active person she described before mesh,

  I feel like this frail older lady now and I hate that. It’s gotta come some time but I’m too young, I feel for all that.

In the Lived Time existential the women describe their active lives before mesh.
What has happened to the body impacts how the women experience time, their past, present and future.

**Lived Time (Temporality)**

Lived time is about lived time rather than objective time. It is about how the past, present and future make up the horizons of a person’s temporal landscape. In this sense it was important to inquire into women’s experience of life before mesh, their day to day experience of the present, and understand the conflict between their previously perceived future and the uncertainty of the future with illness at the forefront of their experience.

Brough explains that to have one, a past, now, or future is necessarily to have the others. The now is never separated from its companion modes of past and future.141 In the midst of living with the impact of complications women’s lived now can dilate to the point where it dominates their experience forcing their past and the present to contract, stranding them in the now, fracturing their sense of continuity through time.

The theme that emerged from this existential was that women were living in the gap between what was and what could have been. Van Manen says most well people have a hope or expectation of their future life to come, but in chronic illness this perspective may be lost142 or simply impossible to attain due to bodily factors. In effect the healthy past is broken off from the ill present, says Charmaz.143

**Life before mesh was great**

The women are clear that it is not their ‘selves’ that they feel bad about (as indicated in the ICIQ-LUTSsqol findings) but the changes to their lifeworld as a result of mesh complications. Their identities have been spoiled due to not being able to return to their pre-mesh state.144

---

144 Dunn et al., “Changed Women,” 133.
Six of seven women were working before their mesh surgeries, and one was studying. Three of the women had worked in businesses with their husbands. All the women talked about how they were fit and healthy, and independent prior to their mesh implantation surgeries.

Ruth described her travels with her husband after they retired,

*LIFE BEFORE MESH WAS GREAT, WE USED TO TRAVEL OVERSEAS ALL THE TIME, AND HAD BEEN TO (NAMES FOUR COUNTRIES), WE’D DONE LOTS OF THINGS. AND YES, SO WE INTENDED TO CARRY ON THAT SORT OF LIFE AFTER WE RETIRED. I WAS WORKING AND WAS FIT AND HEALTHY AND AT THE GYM THREE TIMES A WEEK AND DID YOGA, COULD PLAY WITH THE GRANDCHILDREN AND DO LOTS OF THINGS.*

Gloria also describes an active, happy life,

*I WAS FIT AND HEALTHY, I HAD A JOB AS A TEACHER TEACHING ENGLISH AT A LANGUAGE SCHOOL AND HELPING MY HUSBAND IN A CAFÉ THAT HE BOUGHT TO EASE INTO RETIREMENT...WE WERE VERY ACTIVE. WE RAN MARRIAGE COURSES AT OUR CHURCH, WE WERE HEAVILY INVOLVED WITH LOTS OF THINGS AND VERY CONTENT AND HAPPY IN OUR WORK, AND IN OUR LIVES. I GUESS I WAS FAIRLY INDEPENDENT IN MANY WAYS. I DIDN’T REALLY NEED TO BE LOOKED AFTER LIKE I DO NOW. LIFE WAS TICKING OVER AS IT SHOULD I GUESS.*

Donna and her husband enjoyed working on their lifestyle block and doing everything together,

*WE BOTH WORKED, BUT WE TRAVELLED INTO TOWN TOGETHER AND WE LOVED, WE’VE GOT TWO AND A QUARTER ACRES HERE, AND UM, IT’S A LOT OF ANIMALS, ALPACAS AND THINGS AND WE JUST LOVED IT, GETTING OUT INTO THE GARDEN TOGETHER IN THE PEACE AND QUIET WITH NO NEIGHBOURS...WE USED TO LOVE GOING FOR WALKS, WE USED TO EVEN BIKE, WE USED TO EVEN EXERCISE TOGETHER AND HAVEN’T BEEN ABLE TO DO THAT FOR A VERY LONG TIME. WE HAD TO GIVE UP CAMPING, WE USED TO LOVE CAMPING.*

Julie was constantly on the go,

*I WAS AN EXTROVERT, UM I WAS VERY BUSY, I WAS THE FIRST ONE UP DANCING, I WOULD BE DRAGGING EVERYBODY ELSE UP TO DANCE, I WOULD BE THE ONE THAT JUMPED IN THE CAR AND WENT FOR FIVE HOUR TRIPS TO LOOK AFTER MY AUNTY WHEN SHE WAS DYING...AND JUST JUMPING IN THE CAR AND DRIVING EVERYWHERE REALLY...ALL OVER THE SHOW, I HAD A RELATIONSHIP, I HAD A BLOODY AWESOME SEX LIFE, AND I, IN THE YEAR BEFORE THE OPERATION I SPENT SIX MONTHS OF THE PREVIOUS YEAR IN EIGHT DIFFERENT COUNTRIES AND DID A WHOLE LOT OF HIKING AND TRAMPING. UM, CAME BACK FROM THERE, SO AT THAT STAGE I WAS RUNNING, RENOVATING, YOU KNOW LIKE SANDING, PAINTING, KNOCKING DOWN THINGS, BUILDING THINGS, WATERSKIING*...
Their post-mesh reality is significantly different. The women talked very little in their narratives about the pre-mesh symptoms that led them to get mesh.\textsuperscript{145} This may have been, with the exception of Lisa, because most of the women had minor POP and SUI symptoms that didn’t impact on their day to day lives to the extent that their current mesh complications do.

\textit{I am still just coping week to week and sometimes day to day}

Lundman and Janson suggest that long-term illness requires a revaluation of the self and values, and a sense of being revalued by the world.\textsuperscript{146} Some of the women have struggled to find their value again due to the limitations imposed by mesh complications, and by being unable to ‘do.’ Their efforts are focused on living day by day, closed off to the past and the future, enduring somewhere in-between.

Julie contrasts her-self before mesh, and after,

\begin{quote}
I was a fairytale, happy ever after person you know? Even though it doesn’t do that necessarily, but I could always find a fairytale ending. I don’t do victim very well...So it’s kind a like the stuff I thought I was made of is crumbling a little (shaky voice). And I was brave and I’m not brave anymore, and that’s part of the PTSD...
\end{quote}

And the physical reality in contrast to her previously active self,

\begin{quote}
They gave me a walking stick but refuse to use it cos it kind of screams at me...Sometimes I wouldn’t bother walking to the letterbox which is 30 metres?...some days I wouldn’t even bother with that, other days I can even get round the little block...it totally depends how it’s all unfolding.
\end{quote}

Lisa lives firmly in the now, unable to look to the future until she has laid to rest the trauma of the past,

\begin{quote}
I am challenged with day to day living and trying to rebuild a life around my physical abilities and changes that have occurred in my life. I can’t/don’t look to the future. I am still just coping week to week and sometimes day to day...I am still playing catch up dealing with issues not sorted from the last few years.\textsuperscript{147}
\end{quote}

\textsuperscript{145}Lisa, Julie and Penny had experienced traumatic deliveries.


\textsuperscript{147}Lisa, written submission to Massey University mesh research project, March 2018.
Similarly to the women in Dunn et al.’s study, day to day living for all the women is structured around living and coping with their successive impairments.148

The future is uncertain

Chronic illness doesn’t only cause a disruption in present function, but also affects how the women perceive the future. When we are well, we take for granted that we will have a future where we can achieve our life goals. Chronic illness imprisons the women within the present moment. Toombs describes this as a place where “the future is disabled, rendered impotent and inaccessible.”149

Beth articulates her sense of powerlessness with regard to the future,

Having the mesh problem often gets me down, the length of time gone by, feeling of loss, isolation, loss of purpose, feeling sore most of the time is quite depressing. It’s just the whole issue of trying to find answers, make progress. I keep thinking that if nothing changes what will I do? Having no job, being stuck, stagnated for so long makes me worry about the future, how I will cope etc. I find it really hard because I am (early 40’s) now and still have not been able to make any real progress, things are still not resolved. The problem is even if things were resolved it’s hard to just pick up your life where it was left when a crucial chunk was lost, it stuffs everything up. I find it frustrating because it doesn’t matter how much I try or what I do, I get nowhere which creates a sense of powerlessness to change anything.

Similarly Lisa has some tough decisions to make, with uncertain outcomes,

What do I do from here? Do I have the Monarc sling out as it is wrapped around the ischium and very close to nerve and arteries? Is the mesh causing the pain and leg complications or is it the scar tissue from multiple operations? I can walk now, so do I wait until I can’t walk again for anymore surgery?...The risks outweigh the benefits currently. Can I live long term with limited sitting ability?150

Thoughts of ending it all

Three of the seven women had considered ending their lives due to the unrelenting pain and distress the mesh complications caused them.

150 Lisa, written submission to Massey University mesh research project, March 2018.
In Lived Space we saw how after Donna’s mesh removal surgery she had approached the urologist with further symptoms, but was told that it was not possible that there was any mesh left to cause problems. Donna continues the story,

But as the next few months got on I then got very depressed, the pain was just terrible and I really got, probably that Christmas of (year), I got to my lowest point and it was just awful. I didn’t want to live because I thought, “Well if this is how I am,” you know, “this is just awful.”

She explains,

I feel it is the grief of losing my ‘pre-mesh’ life that brings me down the most, and added to that is the ‘Acute on Chronic’ pain and the disabilities I now live with. In my darkest times I have thought about ending my life, but then I remember all the things I have to live for in life. My family and grandchildren are extremely important to me...

Lisa’s son, who had been helping care for his mum, took his own life after one of her mesh removal surgeries, and as her relationship with his father was ending. This led to a mental breakdown and a period under the care of mental health services. She says, her voice almost a whisper,

My son took his life (pause) using my medication...he tucked me into bed and he took all my medication and I didn’t find him til the morning...Sometimes joining (name) is very inviting.

Julie, who earlier explained that she doesn’t feel like she is living a life, describes hopelessness,

I am not suicidal as such – I just don’t have the courage to do that – but I would rather no longer be here.

Ruth, who is frequently tearful about her situation, cried on the telephone to her GP, who then involved mental health services,

I said, “Yeah well I’m at my wit’s end,” I’m crying on the phone, so she then is, had the mental health onto me, they were worried I’m gonna commit suicide, and I just said, “Well yes, I’m at my wits end”...now ACC are checking too...cos I cry on the phone. So yeah, everybody, I’m not going to commit suicide I’m gonna fight! I’m not going to give in.

What keeps the women going are the other people in their lives, friends, family and for some, God.

151 Donna, private letter to surgeon dated 21 September 2016.
152 Julie, written submission to Massey University mesh research project, March 2018
Lived Other (Relationality)

As Van Manen describes, Lived Other is about our social world and how we relate to others in the inter-personal space. It is also about how we relate to and experience the absolute Other, God.  

As we’ve seen in the Lived Space, Lived Time and Lived Body, the factors discussed in these areas have an impact on women’s social world. The themes Suffering in Silence, and Finding absolute Other, and others a source of strength emerged from the women’s narratives.

It’s not an area one talks about

Suffering in silence refers to the difficulty in talking about the area of the body that is affected by mesh complications, and the social acceptability of doing so. This effectively silences women. Not wishing to be a burden, and wanting to maintain a sense of normality in the social world also prevents women from sharing their journeys with some friends and family. They are unable to publicly lament their suffering.

Maintaining a ‘normal’ life or returning to one becomes the symbol of a valued self, says Charmaz. As Julie’s narrative shows, it takes a lot of energy to hide one’s disability,

I try to pretend that everything’s fine. I’m kinda hopeful that the neighbours haven’t worked out what’s going on. People that I have known for years I haven’t told, because I don’t have a partner anymore, I don’t have any family nearby. I need people to treat me like I’m normal, even if it’s just for the ten minutes that I can handle it. I only started saying I was semi-retired because I’ve got to turn this around to a positive…I thought that actually sounds good, people are gonna think that’s ok.

Disguising or minimising one’s illness or disability to others can be seen as “holding the past as normal” whereas adapting one’s lifestyle around illness can be seen as “making the present normal,” says Bury.

---

154 Charmaz, “The Self as Habit: The Reconstruction of Self in Chronic Illness.”
It is difficult to know with whom and how much to share of one’s lived experience. The greater the risk of judgement, or stigma the woman assesses in the telling, the more likely she is to keep silent.

Penny explains that it’s still not socially acceptable to talk about a woman’s genital area,

*I’ve never talked about it to anybody. The ladies at work knew I had a problem but it’s probably not until I joined Mesh Down Under that I realised that you know actually that I can talk about it. It’s ok if it’s breast cancer, you talk about breast cancer, you talk about prostate cancer but you don’t talk about, or you to do talk about bowel cancer a little bit, but you don’t talk about mesh, and you don’t talk about your vagina or your, to people or...you know it’s almost like you’re suffering in silence because it’s a, not a region that you should be talking about.*

Lisa sees a psychologist regularly, with whom she can talk about living with mesh complications,

*You don’t want to talk to your friends your family and that, that’s not what they are there for, you want to go out and be sociable with them but they don’t need to hear about your health.*

Brocker, Alt, Rzepka, Sohn and Hallscheidt identify that incontinence and POP are still taboo topics in society. Internet support groups such as Mesh Down Under, and others like it, provide a safe place for women to discuss especially personal or sensitive aspects of their condition, connect with others with similar lived experiences, and share information and advice without judgement or stigmatisation from others.

Limited capacity for social interaction

Managing day-to-day symptoms and associated bodily limitations also caused the women’s social worlds to shrink, as their bodies no longer behave according to social expectations.

The Australian Senate Inquiry report outlines how many women described that they had withdrawn from social and family activities, too embarrassed to explain their symptoms to friends or family.157

---

157 Siewert, *Number of Women in Australia Who Have Had Transvaginal Mesh Implants and Related Matters*, 23, Section 2.43.
Julie explained how she steers invitations to evening events like movies, toward having a coffee in the morning instead which she might be able to manage, and says, 

If you keep saying no you can’t come they stop asking you, you don’t get asked any more. You’re off the radar.

She chooses not to be active on social media, saying that it just shows her what she is missing out on.

Gloria talks about the energy required to keep up a positive persona,

I don’t go to book club now and I don’t go to quite a few other things. I don’t go to church because I’m just not up to socialising and sparkling (laughs). And I just don’t have the energy, or the will...I don’t normally talk about the bad side of it because when I’m around people I put on a happy face...You don’t connect with people if your world shrinks...and you don’t have much to offer I suppose.

For Ruth going out causes constant anxiety, with even minor activities of daily living having to be planned. Going out takes it to a whole new level,

And I can’t go out, and staying at people’s places is not the same cos I’m worried, “Am I going to get to the toilet in time? Am I going to mess myself?”

She is also unable to drive long distances, and finds that there is a price to pay, in terms of pain, for any activity,

I can’t drive now. I can drive up to the mall and I often go up there just for a coffee with some friends from the gym...but I pay, suffer for it at night.

Going out takes planning, and spontaneous outings are not possible says Lisa,

Socially I’m limited to where and when I can go, and this does not allow for spontaneous outings. Things I consider when going out are: when do I have to stop drinking beforehand? length of time, availability of bathrooms. I get frustrated at being late but its reality and all I can do is apologise. I have given up on going on spontaneous outings as I always get caught out. 

I hate being a burden

Of the seven women four are married, one is unpartnered, and two have lost their relationships at least in part, as a result of changes mesh complications wrought in their relationship. Those who are married rely heavily on their partners. Some of the women

Lisa, written submission to Massey University mesh research project, March 2018
feel frustrated and guilty when they become aware how much their suffering disrupts their spouses and family’s lives. The wider family system is also affected by the change in roles.

Dunn et al. also refer to the impact on women’s relationships. Both Ruth and Gloria worried what would happen if their husbands became ill, Ruth says,

> He does everything...we’ve been married 51 years so...I couldn’t cope without him. I know I couldn’t, yeah. Well if he gets sick we’re going to struggle.

Gloria shares similar concerns,

> I rely a lot on (husband) and I’m afraid it’s affecting us both, in a way we’ve grown closer, but there’s this underlying anxiety about where this is going to lead. I worry that (husband) will get ill.

For Donna, she feels guilty that she is not able to do her share of the work,

> (Husband) has been wonderful, he’s been my rock. I couldn’t have done this without him. He is so supportive and caring cos it’s affected him hugely...since the mesh I’ve been able to do less and less and in the last, you know, few years I’ve not really been able to do anything. So then I get the guilts of this is too much for (husband) you know, I’m not pulling my weight.

Carel points out that both partners are impacted by the woman’s chronic illness experience, and it is their combined life, projects, and activities that are pared back rather than just those of the woman. Spouses have to live with challenges caused by their wife’s mesh complications, and Eriksson and Svedlund speaking about spouses living with a chronically ill partner, say that they need to find support for living with the spouse’s illness where they can, appreciate the good parts of life that they can still share and adapt to constant changes and an uncertain future.

For those women that do not have partners, their mothers were their main support.

For Lisa, the caring has come full circle,

> My mum has now got early stage Dementia and all these years she’s been my rock, and now it’s my turn to look after her.

Beth says,

---

159 Dunn et al., “Changed Women,” 134.
160 Carel, *Phenomenology of Illness*, 47.
My mum has been my main support person, she has gone through everything with me and so I think she has been amazing. I don’t know what I would have done without her.

Julie is unable to rely on the support of parents as neither she nor her elderly parents can travel, and they live in another country, requiring air travel. She is cognisant of the reality that she may never see her parents face to face again. She talks of her grief around her perceived loss of collective family memories, such as not being in the family photograph and the generational impacts of this.\textsuperscript{162}

She would like to have an intimate relationship again but says,

\begin{quote}
I want a lover not a caregiver...I don’t want to be on my own forever but hey I’m really a grand proposition aren’t I?
\end{quote}

Gloria and her husband had planned to support other members of the family in their retirement, but now find themselves the recipients of their children’s support,

\begin{quote}
Something I find quite hard, is you know instead of this plan to be of great support to our children, they’re beginning to support us, or support me. I’ve got a brother who’s had strokes and the only time my sister-in-law has a break is when we’ve been up there, and we’ve stayed with him. And I haven’t been able to do that this year at all for her.

It’s been a dramatic change from being the carer I’m now being cared for and that’s humbling, which isn’t necessarily a bad thing but I don’t want that to continue if I can help it. I would love to be well. Again. There’s huge needs out there, my world’s shrunk, and what I can do.
\end{quote}

The Australian Senate Inquiry report referred to the deterioration of relationships with family and friends, and how this left women lonely.\textsuperscript{163} This was the case for Beth and some members of her family,

\begin{quote}
It has been quite difficult as I have been rejected and judged by some family members. For example one of my sister has never understood or acknowledged the effect having mesh has had on my life. She has not spoken to me for nearly seven years now as she blames me for everything...Apart from one cousin the rest don’t have anything to do with me, it’s like I don’t exist, to them I have no life so I am not worth knowing.
\end{quote}

Beth’s mesh complications have affected the wider family and caused loss of relationships, leaving Beth feeling isolated and alone.

\textsuperscript{162} Julie, written submission to Massey University mesh research project, March 2018
\textsuperscript{163} Siewert, Number of Women in Australia Who Have Had Transvaginal Mesh Implants and Related Matters, Section 2.60.
I feel quite lonely and segregated as a person it’s been hard living at home because given my age it doesn’t make me feel good about myself. I often feel ashamed because when I compare myself to other people in my age group it kind of makes me feel I failed somehow. For example, most of who I know are married, or have children, got careers and so on, which makes me feel out of place, not normal.

To be honest, I feel like my life has been shredded and left hanging in a whole lot of pieces. The problems caused by mesh for me has almost felt like a life sentence of home detention, it has been so isolating. It has been reduced to a hermit-like existence which I wish with all my heart could have been different. It is not the life I envisioned for myself before I had the surgery. When the mesh was removed I had hoped there would be a big improvement, that my life would change, but it didn’t happen...My life has been ruined by having mesh.

Many of the women were trying to care for family while managing their own health needs and surgeries. Penny was dealing with erosion of the mesh into her vagina when the needs of the wider family took priority,

When I first started getting the erosion we were going through a father-in-law that had died, we had a mother-in-law having to move and deal with who had dementia, we had to move a house of 44 years and they were hoarders (laughs), and then my father got sick...

She later put off a much needed diagnostic colonoscopy because it conflicted with her daughter’s graduation. Similarly Donna had to put off a surgery for several months after her father died. She and her husband also support two of the children from their blended family with mental health challenges. One of the children becomes especially stressed when Donna has surgery, at one stage becoming suicidal just hours before one of Donna’s major surgeries.

I’m comforted by God/My family gives me strength

Similarly to research by Narayanasamy, women that identified their religious and spiritual beliefs as a source of strength in the global spiritual question talked about God as a source of strength in their lives, whereas non-believers talked about family.164 For some women their spouses served as their “rock” and for others their mothers, in the lived other spaces of the women.

Julie talks of a spiritual experience she had the night before her surgery to remove mesh from close to her femoral artery,

It was just before I went to sleep and all of these angels were coming at me, it was just incredible. Angels and angels and angels and it was like from being petrified and doing my will the day before...to having all these angels come at me and I went into theatre as cool and calm as a cucumber. It was just amazing. I knew at that stage whatever the outcome was whether I died or lived it was for a reason...Everything’s ok, if I die it’s for a reason; if I live it’s for a reason.

Gloria articulates her theology of suffering and how her understanding of God’s care helps her,

I’m comforted by God and I’m comforted that He knows and He cares and I know enough, I think I’m mature enough in my faith to know that life is not always sweet and it’s not always roses, um and it’s ok that it doesn’t hurt us to go through a little bit of suffering because we understand others suffering better if we have experienced it ourselves...I think I am buoyed up by my family too and their prayers...I find joy in the small things and can maintain a positive attitude most of the time to cope with trials and uncertainty for the future. People are praying for me so I am very blessed.

Gloria also shared that she believed that it was a season, and that one day she would be through it and be okay.

For Beth it’s important to know that this is not all there is to life, and her hope is in the life after this one,

Most of all I think my belief in God, being a Christian has been a major source of strength for me. It has given me hope in what seems to be a hopeless situation. Ultimately, I trust that God is in control and I can depend on Him. When everything seems hopeless it helps to think you know, that this is not all there is to life. It gives me a different perspective on life and what is important. I believe when people die they go to heaven so while I think I might not get to do much now there is more in life later kind of thing. Other things which have helped me to cope are having some supportive family and friends...For me having a dog as a special companion is also helpful as they provide such unconditional love and acceptance.

Julie talks about not being able to manage to attend church and how it felt incongruous having communion at home,

I don’t go to church because I wouldn’t be able to handle that, and I had the guy coming around to bring communion around but I kinda stopped that, it just felt like hard work. He was very sweet (pause) but we’re on different planets. Better when you’re eighty...
Some focus their anger on God when traumatic life events occur, but the women in my study reported no anger toward God, they accepted that their mesh complications were part of their life stories, and instead used their faith as a resource to cope. They believe that the cause of their suffering is man-made.

Sidell says that families and significant others can assist or hinder the women’s coping. Family members often grieve for the person who is no longer the same.\(^\text{165}\)

The Australian Senate Inquiry received many personal accounts describing the impact of mesh complications on women’s family and personal relationships, with many women writing of their inability to care for the children or interact with their grandchildren.\(^\text{166}\)

Donna, Ruth, and Gloria have grandchildren and shared this frustration, and the limitations on their bodily functioning that make it so difficult. Donna says,

\textit{(Daughter) still needs heaps of help so we have little (boy) twice a week, two nights a week, but then I am so exhausted to have the other children and we need to have the other grandchildren to give their parents a break because (husband’s) daughter’s quite unwell. I love the grandkids but I get very tired with the grandkids but I love doing stuff with them...I find it sad that I struggle to do things with them without compromising my own health.}\(^\text{167}\)

Ruth finds it hard that she can’t do with her latest grandchild what she had been able to do with her previous grandchildren,

\textit{I can’t pick up my grandkids, and...the new one we’ve got I can’t pick him up and play with him like I did with the others.}

\textit{What is done is done}

To reconfigure their lives around their limitations is a major task for the women, and requires a degree of acceptance of all that which has been lost, and what remains. Similarly to the findings of Dunn et al. some of the women are very pragmatic, others feel they need acknowledgement, to see system change, and to warn other women\(^\text{168}\) before they can move from grief to gentler chronic sorrow.\(^\text{169}\)

\(^{165}\) Sidell, “Adult Adjustment to Chronic Illness,” 8.
\(^{166}\) Siewert, \textit{Number of Women in Australia Who Have Had Transvaginal Mesh Implants and Related Matters}, Section 2.46.
\(^{167}\) Donna, private letter to surgeon dated 16 September 2016.
\(^{168}\) Dunn et al., “Changed Women,” 134.
Donna contrasts who she was before mesh and how she is now,

Prior to having mesh implanted into my body I was a hardworking, strong woman that loved life and especially the outdoors. I am now a tired, in constant pain, disabled woman who cannot enjoy the things I used to love...Bottom line for me is—mesh has had a significant negative impact on my life since it was first implanted in 2008...but I am a fighter and hard as it is, I will get through this the best I can for the rest of my life.\(^{170}\)

Lisa is gracious toward those who have caused her so much suffering, and resigned to the losses she has experienced,

I am not bitter towards the doctors over the mesh as I know they were trying to do their best, but much of the problems the mesh has created are outside their expertise. We are all only human. It is only now 10 years too later for me, that doctors are realising that full removal is the best choice. The multiple partial removals have caused multiple problems.\(^{171}\)

It’s too late to be bitter, it’s too late, it’s all water under the bridge, too much has happened with losing my marriage, my son, everything, it’s like it’s kind of minor now, it probably would have had more of a mental impact if I’d known back then...so it’s kind of like water under the bridge now.

Donna expresses similar sentiments and highlights that acceptance is not a one-off process,

What’s done is done and now it is just about making the best of your life that you can. Lots of changes, lots of modifications, you can’t do what you used to, it’s, acceptance was very hard for a long time, and I still struggle with it especially when I get frustrated that I can’t do something I used to do and enjoy...

Ruth has not yet reached this point, perhaps because she is yet to undergo treatment for her complications. She wants acknowledgement and an apology, and needs these for herself, and for others to be able to move forward,

I still want an apology from the doctor that did this, I want him to realise, one day I want to be here when they realise that they’ve done this to us. That’s, I want that acknowledged, or ACC acknowledge that we all need this fixed.

generate a situation where there is a disparity between the current reality created by the losses and the desired reality. Chronic sorrow is cyclical and continues as long as the disparity created by the loss remains. It is estimated that around 80-90% of people with chronic illness experience chronic sorrow. This is an area requiring further research, potentially chronic sorrow could relate to Paterson’s disappearing/dys-appearing body, and associated sense of control/powerlessness.

\(^{170}\) Donna, private letter to surgeon, dated 16 September 2016.

\(^{171}\) Lisa, submission to Massey University mesh research project, March 2018.
The women know they will not get their pre-mesh lives back but they want all that they have suffered, and lost, acknowledged. They want to see the health and regulatory systems accept mesh complications as treatment-injury related, and to prevent other women from suffering as they have.
Summary

This research has sought to address a gap in the research literature about the experience of women living with pelvic surgical mesh complications, with the aim of revealing the breadth and depth of existential impacts that arise from the disruption to the embodied self.

Dunn et al. say that surgeons should recognise and acknowledge the “emotional” journey that women with mesh complications are on, and Welk et al. suggest that surgeons become aware of the “serious psychological implications” for women with mesh complications. My research has demonstrated that the impact of mesh complications is far wider than just emotional, or psychological, it reaches the furthest boundaries of the women’s lifeworlds.

As the ICIQ-LUTS-sqol scores indicated, the women reported significant adverse impact on quality of life across the twenty domains assessed, and the additional areas they revealed in their narratives.

Women with mesh complications experience disruption of their selves as embodied persons, as women, mothers, grandmothers, wives, sisters, aunties and friends. They struggle to make meaning of what has happened to them.

They find that their bodies can no longer be relied on, and that they must make significant adaptations to their day-to-day lives to continue to function. Family systems are affected as they are unable to perform their former roles and economic impacts from loss of employment causes a drop in their standard of living, and will continue to do so in the future.

They experience cumulative losses and the grief that results – from the loss of bodily function, job and related identity, roles, and social contact, and they fear being a burden on their loved ones and families.

The women find themselves stuck in the “now”, unable to return to their pre-mesh selves, or to participate in the taken-for-granted futures that they formerly perceived for themselves.

They find that the genital area of a woman’s body remains an area that is not socially acceptable to talk about and this silences them, in terms of being able to lament their suffering, and sorrow, and find solace in others.

172 Dunn et al., “Changed Women.”
174 Such as the medical practitioner: patient relationship, medical Trauma, pain, uncertain future, suicide, taboo.
Some find comfort in God, and this helps them find meaning and hope in their suffering. For other women their families are a source of strength and what keeps them going when their suffering seems unbearable and life hopeless. For some of the women it has been only thoughts of family that have kept them from taking their own lives when it all got too much.

Denial of the women’s experience has led to a loss of hope for some, hope in the medical profession and wider health system to help them, hope for a future that is pain free, and hope for sufficient strength for life as they would like to live it. It is difficult for the women to maintain hope while they perceive that others are unwilling to care about their suffering.

Despite their experiences, they have shown extraordinary resilience and courage in the face of the devastation that mesh complications have wrought in their lives. They have suffered as a result of industry, regulatory, wider health system, and health professional lack of acknowledgement of the centrality, sensitivity and sacredness of a woman’s genital region to her embodied, as-lived experience and lifeworld.¹⁷⁵

Theological Reflection

My research has answered the questions, what is happening? (The experience) and why is it happening? (Analysis). It has also answered some aspects of what does it mean? This reflection will add to this last question, and provide insight into how best to respond pastorally to women living with mesh complications.

(Based on the pastoral spiral of Green)\textsuperscript{176}

In looking to scripture to reflect theologically on my research, I considered Job and what his experience teaches about suffering, and Paul with his thorn in the flesh (2 Cor 12:7-9). Metaphorically Paul’s description of his affliction is similar to how the women describe the experience of living with erosion, feeling like they have “barbed wire” or a “saw” in the flesh. However the story of the haemorrhaging woman of Mark 5:25 has stood out to me from the beginning, largely because of the similarities in the little that we know and can assume of her lifeworld, to the lifeworld’s of the women in my research. The following is not an attempt to exegete the passage, but to look at commonalities in Mark’s narrative with the experiences of women in my research, and propose a framework for pastoral care of these women.

To set the scene, Jesus and his disciples, along with a large crowd who are following are on their way to the house of Jairus, a community leader, whose daughter is “at the point of death” (v23). There is a sense of urgency. However on the way a woman in the crowd who has been bleeding for 12 years touches Jesus’ garment in the belief that doing so will make

\textsuperscript{176} Green, Let’s Do Theology.
her well, and Jesus stops to find out who has been the recipient of the power he felt go out of him (v30).

Like the haemorrhaging woman in Mark 5:25-34, the women in my research have endured much under many physicians, spent all they had had; and are no better, but rather grow worse (v26). Some have been given up on as being incurable. Their strength for life is impaired.

The haemorrhaging woman shows “desperate courage” in approaching Jesus in a public place (even if it was from behind), risking ridicule and punishment as she was considered unclean, and is socially isolated due to her constant flow of blood. Anyone she comes into contact with will be considered unclean.

When the woman encounters Jesus after touching his clothes and feels that she has been healed bodily (v29), Jesus asks who touched him (v30). Rambo says he has in effect been a “witness” to this healing rather than initiator as he is in other healings in the gospels. The woman, in fear and trembling, falls down before him and tells him the whole truth (v33). This likely summarised her lived experience across more than a decade, and the desperation that drove her to covertly seek healing by touching Jesus’ garment without his knowledge. This could not have been a brief interaction.

In the same way that this woman upsets the system of legal purity of the day and the social discriminations that derive from it, modern day women with mesh complications are similarly desperate, defined by their illness and forced to “go public” with their private tragedies about a socially taboo region of the body to try to get help.

Jesus, unrushed, listens to the woman’s narrative from an I-Thou stance (little does she know that she is in fact encounter the eternal Thou), in doing so affirming that she is more than her illness, and acknowledging her embodiedness, humanising her. Had he not wanted to know who had touched him and spoken with the woman, she may well have gone away physically healed, but lacking healing in the social and spiritual dimensions.

With her healing not yet complete, Jesus calls her “daughter”, saying, “your faith has made you well, go in peace, and be healed of your disease” (v34). In calling her daughter he declares a connection between them and in doing so acknowledges her healing before all

177 As described by Robin G. Branch, in her work “A Study of the Woman in the Crowd and Her Desperate Courage (Mark 5:21–43),” In Die Skriflig/In Luce Verbi 47, no. 1 (November 29, 2013), https://doi.org/10.4102/ids.v47i1.649.
178 Mark 5:28 “If I but touch his clothes I will be made well” (Sōzō – delivered from suffering and sickness), 5:29 “She felt in her body that she was healed of her disease” (Iaomai – healed bodily), 5:34 “He said to her, “Daughter your faith has made you well, go in faith and be healed of your disease,” (Hugiēs – sound, whole in health), NRSV.
180 As described in Buber and Kaufmann, I and Thou, 123.
those present, restoring her to her community. She now needs to go and reconstruct her story, and be revalued by society.

**Pastoral Response**

Jesus’ ministry to the woman is a model for us, as he restores the woman’s “strength for life.” Her bodily healing was only one part of a more holistic restoration. In his interaction with the woman he models, (1) Acknowledgement of the power of faith, (2) I-thou relationship, (3) making space for, hearing and holding a person’s story, and (4) restoration of the person to the community and the community to the person.

**The Power of Faith**

Swinton says that we do not suffer in a vacuum, “suffering is always mediated by our social context, our beliefs about ourselves, others, God and the nature of reality.” For Christians their suffering is different in the sense that they are able to place suffering in a framework of hope and new possibilities, understanding that God is in control and moving them toward a hopeful outcome.¹⁸¹ Thus faith is closely connected to hope. Beth’s narrative in the Lived Other section demonstrates this. Pastoral caregivers can affirm this and would consider this a familiar part of their usual practice.

Hunsinger refers to Christians being upheld by the prayers of others when they have no access to hope themselves, and Gloria and Ruth (though this section of Ruth’s narrative is not quoted) both mention this being of value in their narratives.¹⁸²

For women who do not have a personal faith, pastoral caregivers should look to strengthen other supports such as family and spousal relationships (as identified by the women in my research) that give them meaning, and purpose.

Establishing what gives women hope then developing ways to sustain it is vital.

**I-Thou relationship**

---


The haemorrhaging woman of Mark 5 encountered the eternal Thou, that being God embodied in Jesus. As pastoral caregivers we represent the eternal Thou in our pastoral encounters. One of the luxuries that we have as pastoral caregivers is the luxury of having the time to simple “be” (I Thou function) without having to “do” (I-It function in some situations e.g. surgery) as health professionals do. They have to constantly balance the dynamic of I-Thou and I-It relationship, within the context of providing health care that often demands both.

Approaching the pastoral encounter from an I-Thou perspective allows the pastoral caregiver to connect with women as unique, embodied, and relate to their first-person perspective of how life is for them.

If we take Cohn’s Buberian continuum and adapt it a little further we can see that it represents pastoral care as well.

![Diagram adapted from Cohn, 2001.]

Within an I-Thou relationship pastoral caregivers can help women understand that they are more than their mesh complications (although at times they may not feel like it as their symptoms constantly bring it to the fore of their day to day existence, along with the associated feelings of powerlessness). Acknowledging this, and the women’s suffering, resilience, and courage in the face of such disability is important.

It is only in an I-Thou relationship that trust can develop and we can access the “whole truth” of women’s stories. Doehring says this is important because if trust is present the caregiver can be entrusted with bits and pieces of stories and especially the “undigested” emotional reiterations of trauma that might not otherwise be shared.

*Making space for, hearing and holding the story*

---

183 Cohn, “Existential Medicine.”
184 Doehring, *The Practice of Pastoral Care*, xv.
Essentially the pastoral caregiver is a compassionate witness.\textsuperscript{185} This was the most important thing to the women in the research, being able to break their silence, and talk about what had happened to them and the impact it had on their lives with someone who would understand the as-lived experience. The interviews were cathartic for some, enabling them to construct a cohesive narrative and make sense, and meaning of their journeys, having previously been able to share only symptomatic aspects of their experience as part of medical or ACC processes. Understanding the meaning that women attach to their experience, and suffering, and the disruption to their lifeworld’s is crucial to any healing process.

It is important for pastoral carers to make space where the story can be told without time limitation, taking into account the women’s need to position her body comfortably (that may standing, lying or kneeling as the women did as they were interviewed). Doehring encourages the sense of being fully present in the moment, without it being overshadowed by losses from the past or fears about the future. She says that then both pastoral caregivers and care seekers can experience a sense of God’s presence and the sacredness of life, and find strategies to have more of these moments.\textsuperscript{186}

Abraham says listening is a spiritual act because it reflects the nature of our relationship with a listening God who listens and attends to our most private expressions of pain, and distress.\textsuperscript{187} Listening is a key part of being a compassionate witness. It doesn’t remove the pain of trauma, but reconfigures it through restoring human connection, building strength and hope, says Hunsinger.\textsuperscript{188} It is in this way that we can bear one another’s burdens (Gal 6:2, 5).

A key part of this is listening to the women’s lament, being fully present and hearing the grief, the pain, the injustice. Lament gives language to the anguish that speaks against the way things are, in the hope that the way things are is not the way they will always be. The function of lament is rehabilitation, says Swinton.\textsuperscript{189}

Pastoral caregivers need to be prepared to hear about vagina, bowel and bladder, and sexual dysfunction if they are to fully understand the grief behind the loss of sexual relationship, or the reasons why a woman finds it difficult to care for her family, or participate in her community. This is where it can be useful to have a pastoral caregiver with a health background.

\textsuperscript{185} Hunsinger, \textit{Bearing the Unbearable}, 22–41. Hunsinger references the work of Kaethe Weingarten in relation to compassionate witnessing, and describes four possible “witness positions, the most ideal being “Aware and empowered” where the witness experiences themselves as effective in what they care called to do and has an awareness of the suffering of those they serve as well as a sense of empowerment in relation to that suffering (p27).

\textsuperscript{186} Doehring, \textit{The Practice of Pastoral Care}, 141.

\textsuperscript{187} Abraham, “Reflections on Narrative in Pastoral Theology,” 727.

\textsuperscript{188} Hunsinger, \textit{Bearing the Unbearable}, 25.

\textsuperscript{189} Swinton, \textit{Raging with Compassion}, 105, 106.
It is not the pastoral caregiver’s role to explain the origin of the suffering, as Job’s friends tried to do, or to minimise its impact. They are there simply to share it and convey it to God, says Hunsinger.190

**Restoration of the person to the community and the community to the person**

Just as Jesus brought the haemorrhaging woman back from the margins, this too is a role for pastoral caregivers. Instead of marginalising those who are ill, we are to recognise that when one person is ill, the whole of society is ill. Lammers and Verhey say, just as the parts of the body do not work in isolation, in our humanity we are interdependent; the answer lies not in isolation, but fellowship (1 Cor 12:26, Ro 12:15).191 Frank says it is the support of one’s community that makes suffering liveable.192

We need to restore a sense of place, and a sense of togetherness, of journeying alongside. These women are the mothers, daughters, sisters, and aunts in our communities. Their suffering impacts the whole community. We need to seek them out when they are absent, and as we do with others with disability we need to find out what their specific needs are in community, and what we can do to meet them.

Final thoughts

As I outlined in the introduction, pastoral caregivers are called to stand up for the marginalised and against disempowering discourses, to take a moral stance, something that we are often reluctant to do in a secular health environment.

To truly understand a person’s suffering we need to understand their lived experience, and lifeworld. This is where qualitative research, in unison with theology can be of service in pastoral care. Returning to Swinton’s words from the Introduction, this is how we can learn new embodied spiritual truths, and gather deep and meaningful insights into the experience of illness. Sharing these insights with the healthcare team, and those who regulate and have oversight of the healthcare system can help inform policy and practice that enables embodied-person centred care.193

At the heart of our pastoral theology is that the knowledge that while cure may not be possible, or healing certain, care is always possible.

190 Hunsinger, *Bearing the Unbearable*, 95.
References


Boer, T. A. de, D. A. Gietelink, and M. E. Vierhout. “Discrepancies between Physician Interview and a Patient Self-Assessment Questionnaire after Surgery for Pelvic Organ Prolapse.”


Laso-García, Inés M., Miguel A. Rodríguez-Cabello, Miguel A. Jiménez-Cidre, Andrea Orosa-Andrada, David Carracedo-Calvo, Luis López-Fando, and Francisco J. Burgos-Revilla. “Prospective Long-


Milani, Alfredo L., Anne Damoiseaux, Joanna IntHout, Kirsten B. Kluivers, and Mariella I. J. Withagen. “Long-Term Outcome of Vaginal Mesh or Native Tissue in Recurrent Prolapse: A Randomized


Appendices
Appendix A – Annotated Timeline Pelvic Surgical Mesh

1948
The use of nylon mesh for hernia repair is pioneered by French surgeons Acquaviva and Bourret.

1960’s
Polypropylene mesh is commonly used for hernia repairs.

1992
Polypropylene mesh is first used in the female pelvis for vaginal vault prolapse.

November 1996
The US Food and Drug Administration (FDA) approves Boston Scientific’s ProteGen sling under 510k ruling predicated on previous hernia mesh devices.

January 1998
Johnson and Johnson’s tension-free vaginal tape (TVT) is given approval based on its similarity to ProteGen.

January 1999
The ProteGen sling is recalled after numerous injury complaints.

March 1999
The FDA determines the ProtoGen does not function as intended and Boston Scientific recalls it.

2002
The FDA clears the first surgical mesh for the treatment of POP.

2005
Surgical mesh is commonplace in NZ surgeries (exact date of first use unknown)

March 2005
Johnson and Johnson introduces Gynecare ProLift to the market three years before FDA approves it.

April 2007
A Cochrane Review finds insufficient evidence to support the safety of surgical mesh for POP.194

October 2008

A US FDA Public Health notification is released to alert clinicians to more than 1000 cases of adverse events related to transvaginal POP and SUI mesh.195

NZ regulator Medsafe conducts its first review of the use and adverse effects associated with the use of mesh.

2009

Medsafe writes to the Chief Executive Officers of both private and public hospitals using mesh outlining the key points from the 2008 review, and supporting guidance provided by the Royal Australian and NZ College of Gynaecologists. They conclude that when the mesh is used as per manufacturer’s directions for use that the devices not represent a safety risk to patients.

August 2010

A National Center for Biotechnology study finds a high vaginal mesh erosion rate.

September 2011

The US FDA releases a second safety communication stating that mesh related adverse events are “not rare.”196 It considers reclassifying mesh for POP repair from Class 2 to Class 3 (which would require manufacturers to provide clinical data). The four largest manufacturers establish a Transvaginal Mesh Working Group in response but insist that POP meshes remain in Class 2.

July 2012

The US FDA under section 522 of the Federal Food, Drug and Cosmetic Act orders 34 manufacturers of surgical mesh for POP to conduct post-market surveillance studies to address safety concerns. Johnson and Johnson stops selling Gynaecare ProLift, Gynaecare TVT Secur, Gynaecare+M and Gynaecare Prosima. Bard and Ethicon withdraw their products from the US market.

2013

---

195 Schultz, “FDA Public Health Notification: Serious Complications Associated with Transvaginal Placement of Surgical Mesh in Repair of Pelvic Organ Prolapse and Stress Urinary Continence.”
Medsafe publishes the first “Adverse Event Reports Relating to Surgical Mesh Implants, Summary of reports received by Medsafe.”

October 2014

UK’s Medicine’s and Healthcare Products Regulatory Agency deems mesh implants “safe and effective” for most women.

Two New Zealand women experiencing mesh complications, Carmel Berry and Charlotte Korte, take a submission to the Parliamentary Health Committee requesting an independent inquiry into the safety of surgical mesh in New Zealand. Included in an appendix to their submission are narratives from women experiencing mesh complications which evidenced the wide-ranging impact of complications on women’s lives and highlight psychological and social impacts.

The Health Committee is sympathetic, but stops short of banning mesh, making several recommendations. These are to establish and maintain a centralised surgical mesh registry, improve informed consent for mesh procedures, develop a coding system for health providers to allow patients with mesh complications to be identified and monitored, encourage the reporting of mesh-related adverse events, educate surgeons on implanting and explanting mesh, and expand Medsafe’s role to assess quality and safety of medical devices before they are used in New Zealand.

The National government is slow to act on the recommendations, and progress further delayed by the development of a new therapeutic products regime.

2015

Medsafe writes again to Chief Executive Officers of District Health Boards and private surgical hospitals to advise on the latest information relating to the use of surgical mesh for urogynaecological procedures. The letter outlined that surgeons should refer to the latest research and emphasised informed consent that includes both the risks and benefits. The letter states that Medsafe does not feel regulatory action is appropriate.

October 2015

Scottish government reviews transvaginal mesh implants and recommends an informed consent process.\textsuperscript{197}

December 2015

The National Health Service (UK) releases a report saying more research is needed into the risk of mesh.

January 2016

The US FDA increases restrictions for implants from Class 2 to Class 3 (high risk medical devices).

April 2016

The FDA, working with manufacturers and other companies establishes Pelvic Floor Disorders Registry.

Dec 2016

The Lancet reports on Scottish data that women with mesh are three times more likely to have complications.\textsuperscript{198}

2017

National Institute for Health and Care Excellence (NICE) guidance says POP mesh should only be used in the context of research.\textsuperscript{199}

January 2017

The PROSPECT study is published (UK multi-centre study) and concludes that there is no benefit from first prolapse repair with mesh or biological graft.\textsuperscript{200}

March 2017

The Scottish government says mesh doesn’t offer any benefit in treatment of POP.

The Australian Senate Inquiry starts.

The Australian case against Johnson and Johnson starts.

November 2017

Australia bans the use of surgical mesh for the treatment of POP.

December 2017

Medsafe uses section 38 of the Medicines Act 1981 to request safety information from four POP mesh suppliers, resulting in the withdrawal of these meshes from the NZ market. One SUI mesh is also withdrawn, but other SUI meshes continue to be supplied.


\textsuperscript{200} Glazener et al., “Mesh, Graft, or Standard Repair for Women Having Primary Transvaginal Anterior or Posterior Compartment Prolapse Surgery.”
January 2018

The UK conducts a large scale retrospective audit of all women who have received pelvic surgical mesh.

March 2018

The Australian Senate Inquiry report into transvaginal mesh implants released.\(^{201}\)

May 2018

The NZ Director-General of Health writes to all Chief Executives of District Health Boards, and private surgical hospitals updating them on developments in relation to pelvic surgical mesh and asking them to ensure that the relevant staff are aware, following Royal Australia and NZ College of Gynaecologists) RANZCOG guidelines and discussing how best to help women with mesh complications.

July 2018

The UK National Health Service ‘pauses’ SUI mesh use.

The National Institute for Health and Care Excellence (NICE) advise of a delay in publishing mesh guidelines by two months, now expected in April 2019.

October 2018

Greg Hunt, Health Minister apologises to Australian women affected by transvaginal mesh.\(^{202}\)

November 2018

The Australian Commission on Safety and Quality in Healthcare releases three care pathways for the management of POP, SUI and mesh complications.

December 2018

RANZCOG Chair Steve Robson apologises to mesh injured women.

December 2018

The New Zealand Government asks people injured by mesh to register their interest in sharing their experiences to improve patient safety in the future.

\(^{201}\) Siewert, *Number of Women in Australia Who Have Had Transvaginal Mesh Implants and Related Matters.*

To date there has been very little *practical* assistance for affected NZ women. Work is ongoing between the Accident Compensation Corporation, Medsafe, the Ministry of Health, and the Royal Australian and New Zealand College of Obstetricians and Gynaecologists, and Mesh Down Under advocates to improve informed consent, coding, consider a surgical mesh registry, and develop Patient Clinical Care Pathways for women with mesh complications.
Appendix B – Media Reports

In July 2017 the Australian paper the Newcastle Herald framed the debate in contrasting women’s experience with those of sexual abusive victims. The article quotes the oral submission of Health Issues Centre Chief Executive Danny Vadasz. Mr Vadasz identified a number of system issues and the impact it had on affected women, saying that the pelvic mesh scandal had revealed a health system that was “asleep at the wheel,” and that silenced and blamed victims similar to the treatment of institutional child sexual abuse victims. He outlined how the burden and proof of responsibility for raising serious health issues was left “with the people who suffered in the first place,” saying that regulators had chosen “denial rather than acknowledge system failure.” He also alluded to the utilitarian approach taken by proponents saying, “Much of the debate about the severity of this problem has been framed in terms of the good outcomes of the many outweighing the unfortunate experiences of a few.” He referred to the “human dimensions of this tragedy” and said that many of the victims had been characterised as outliers who were unrepresentative of the silent majority, which left many women doubting their own lived experience.203

In August 2017 The Press highlighted political disinterest and inaction when it carried the headline “Minister ‘fobs off’ victims of mesh” going on to explain that then Minister of Health Jonathan Coleman gave Mesh Down Under Advocates Charlotte Korte and Patricia Sullivan 15 minutes to discuss the issues around surgical mesh, and the Ministry’s progress on implementing the recommendations of the 2014 Health Select Committee. The article reports that the Minister deflected questions to his advisers, asking the women to put their concerns in writing. Korte and Sullivan are quoted as saying, “It was soul-destroying.”204

The same year an article by reporter Harriet Marsden in the UK Independent Online focused on aspects of sexuality. In the introduction Marsden says the mesh scandal is about, “shame, stigma, suffering, silence,” and that it is “rooted in sexism and a lack of value placed on female sexuality.” Marsden quotes Kath Sansom, face of the UK mesh advocacy group Sling the Mesh as saying, “Half the women I spoke to said they felt they had been sexually neutered.”205

Concurrent with the Australian Senate Inquiry in August 2017 was the class action where a group of more than 700 Australian women took a case against Johnson and Johnson, one of the manufacturers of surgical mesh. A series of emails presented during the case were

referenced in an article from ABC News titled, “Emails show doctors’ bizarre attitudes towards women’s health.” The article quotes one of the Johnson and Johnson doctors as saying, “It is no less true that sodomy could be a good alternative” for women for whom vaginal sexual intercourse was too painful.\footnote{Sophie Scott and Alison Branley, “Emails Show Doctors’ Bizarre Attitudes to Women’s Health,” \textit{ABC News}, August 15, 2017, https://www.abc.net.au/news/2017-08-15/emails-show-doctors-bizarre-attitudes-to-womens-health-problems/8805710.}

A News.com.au article reveals that this was not an isolated attitude. The headline is “Medic ‘aghast’ at sex advice given to pelvic surgical mesh victims” and relates to Federal senators speaking at the Australian senate inquiry. The article states, “Women unable to have vaginal sex after having mesh implanted “repeatedly” reported that their doctors suggested anal sex as an alternative, Federal Senators told an inquiry in Perth...” and quoted urogynaecologist Dr Michelle Atherton as saying, “I’m truly shocked that a colleague would say that to a woman. I am aghast. I feel awful.”\footnote{“Medic ‘Aghast’ at Sex Advice given to Pelvic Mesh Victims,” \textit{News.Com.Au}, August 26, 2017, https://www.news.com.au/lifestyle/real-life/news-life/medic-aghast-at-sex-advice-given-to-pelvic-mesh-victims/news-story/83e521c5b8a34f1cbd84c2d1c6cd70b.}

Soon after the Australian regulator banned the use of transvaginal mesh for POP, The Christchurch Press led with a front page article, “Mesh Axed from Supply” as New Zealand followed suit. Associate Minister of Health Julie-Anne Genter was quoted as saying, “People need to be able to trust that when they go to the health system they will get assistance and aid to help them. Today’s step is an important step in restoring faith in our medical system to do the right thing.”\footnote{Cate Broughton, “Mesh Axed from Supply,” \textit{The Press}, December 12, 2017.}

The UK’s The Guardian took a statistical approach, reporting in January 2018 that the NHS would undertake a full retrospective audit of vaginal mesh surgery procedures. The article was titled, “Vaginal mesh review to investigate the true scale of complications” and reported that while official guidance suggests a complication rate of 3-5% that current research has suggested the true complication rate could be between 10-15% with 1 in 15 women subsequently requiring partial or full removal of their mesh implant.\footnote{Hannah Devlin, “Vaginal Mesh Review to Investigate the True Scale of Complications,” \textit{The Guardian}, January 30, 2018, https://www.theguardian.com/society/2018/jan/30/vaginal-mesh-review-to-investigate-true-scale-of-complications.}

In October 2018 the Australian, The Guardian carried an article, “Greg Hunt apologises to women affected by ‘horrific’ transvaginal mesh scandal.” Health minister Greg Hunt issued an apology on behalf of the government to women affected by the transvaginal mesh scandal. He is quoted as saying, “I acknowledge the strength of the women who spoke at public hearings, recounting deeply private and often traumatic experiences...Our main aim
and collective efforts are focused on restoring affected women’s confidence in our healthcare system, now and into the future.”

Also in October, after Coroner’s findings were released The Press ran an article titled, “Auckland woman dead after two years of pain from surgical mesh.” Sarah Collis had surgery for POP and SUI and suffered “constant and excruciating pain” for more than two years after surgery. Sarah died from multiple drug toxicity after taking analgesia and going to bed for a rest while her husband took their two young children out.

In November 2018 the Honorable Julie Anne Genter, Associate Minister of Health released statement to media calling for people to register their interest in sharing their surgical mesh experiences. This is a precursor to a national “roadshow” whereby women, and men affected by surgical mesh will be able to share their lived experience of mesh complications with the aim of improving patient safety in the future.

210 Davey, “Greg Hunt Apologies to Women Affected by ‘horrific’ Transvaginal Mesh Scandal.”
### Appendix C – Forms of Humanisation and Dehumanisation

<table>
<thead>
<tr>
<th>Forms of Humanisation</th>
<th>Forms of dehumanisation</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Carrying a view of living life from the inside. Only individuals themselves can be the authorities on how this inward sense is for them.</strong></td>
<td><strong>Insiderness</strong></td>
</tr>
<tr>
<td><strong>Experiencing oneself as making choices, with the possibility of freedom to be and act within certain limits.</strong></td>
<td><strong>Agency</strong></td>
</tr>
<tr>
<td><strong>To be human is to actualise a self that is unique; we are always more than the sum of the parts.</strong></td>
<td><strong>Uniqueness</strong></td>
</tr>
<tr>
<td><strong>To be human is to be in community: our uniqueness exists in relation to others. This dimension of togetherness makes possible the experience of empathy.</strong></td>
<td><strong>Togetherness</strong></td>
</tr>
<tr>
<td><strong>To be human is to care for the meaning of things, events and experiences. Within this context we are story makers and storytellers.</strong></td>
<td><strong>Sense-making</strong></td>
</tr>
<tr>
<td><strong>To be human is to be on a journey. We live forward from the past; how we are in any moment needs to be understood in the context of a</strong></td>
<td><strong>Personal journey</strong></td>
</tr>
</tbody>
</table>
To be human is to come from a particular place; such a habitat is not just a physical environment but a place where the feeling of at-homeness becomes meaningful.

<table>
<thead>
<tr>
<th>Sense of place</th>
<th>Dislocation</th>
</tr>
</thead>
<tbody>
<tr>
<td>A sense of place is lost or obscured. People are challenged to find a sense of place in a new and unknown culture where norms and routines are alien to them.</td>
<td></td>
</tr>
</tbody>
</table>

When unpreoccupied with the vicissitudes of bodily attention, embodiment supports us in moving out into the world, attentive to people, places and tasks in life.

<table>
<thead>
<tr>
<th>Embodiment</th>
<th>Reductionist body</th>
</tr>
</thead>
<tbody>
<tr>
<td>There is an overemphasis on signs and symptoms and the body as separate from broader contexts such as psychological, environmental, social and spiritual matrices. E.g. disbelief of pain because no evidence shows up in physical tests.</td>
<td></td>
</tr>
</tbody>
</table>

(Diagram adapted from Todres et al, 2009).
Appendix D – Consent Form

What is the experience of women living with pelvic surgical mesh complications?

Principal Investigator: Professor Murray Rae, murray.rae@otago.ac.nz 0210747088

CONSENT FORM FOR PARTICIPANTS
Following signature and return to the research team this form will be stored in a secure place for five years.

Name of participant:.................................................................

1. I have read the Information Sheet concerning this study and understand the aims of this research project.
2. I have had sufficient time to talk with other people of my choice about participating in the study.
3. I confirm that I meet the criteria for participation which are explained in the Information Sheet.
4. All my questions about the project have been answered to my satisfaction, and I understand that I am free to request further information at any stage.
5. I know that my participation in the project is entirely voluntary, and that I am free to withdraw from the project at any time without disadvantage. I know that I am unable to withdraw my interview transcript once I have reviewed and approved it.
6. I know that the questionnaire, and interviews will explore my experience of living with pelvic surgical mesh complications and that if the line of questioning develops in such a way that I feel hesitant or uncomfortable I may decline to answer any particular question(s), and/or may withdraw from the project without disadvantage of any kind.
7. I know that when the project is completed all personal identifying information will be removed from the paper records and electronic files which represent the data from the project, and that these will be placed in secure storage and kept for at least five years.

8. I understand that the results of the project may be published and be available in the University of Otago Library, but any personal identifying information will remain confidential between myself and the researchers during the study, and will not appear in any spoken or written report of the study.

9. I know that there is no remuneration offered for this study, and that no commercial use will be made of the data.

Signature of participant: ___________________________ Date: ___________________________

Name of person taking consent: ___________________________ Date: ___________________________
Appendix E – Introducing the Women

Lisa lives alone, her marriage relationship having broken up early on in her POP journey. She is not currently in full time paid employment due to her inability to work because of the physical effects of her mesh complications, specifically chronic pain, limited bowel and bladder control and her inability to sit for any length of time. Unable to sit, Lisa stood for the duration of our 1.5 hr long interview.

Julie also lives alone. Like Lisa, her relationship broke up early in her journey with surgery for SUI, and subsequent surgeries for complications. She had been working a few hours a week from home up until just prior to our interview when this work finished. She lives in what she calls a “nana flat” with her dog for company. Julie had asked her home help to position the couches together so that we could both lie down for the interview.

Ruth lives with her husband. She is retired, having given up work after experiencing complications from a surgery to correct SUI. She has trouble walking due to pain in her groin and struggles with any physical activity, and driving as a result. She is yet to receive treatment for her complications. Ruth was tearful throughout the interview.

Beth lives with her parents. She has been unable to leave home due to complications from her surgery to treat POP. She is unable to work due to activity-related pain, and the inability to sit for any length of time. I was the first woman that she had had contact with that had also experienced mesh complications. Unable to sit, Beth knelt on the floor in front of me for the interview.

Gloria lives with her husband. They are both retired, with Gloria having to retire early due to complications. Gloria has suffered from recurrent urinary tract infections for the last ten years making her feel constantly unwell aside from the days she is on antibiotics.

Penny lives with her husband. She still works three days a week but finds it a struggle at times. Penny was able to sit for the interview but had to sit skewed with her weight on one buttock to be comfortable.

Donna lives with her husband. At the time of our interview she was facing another surgery to remove further mesh. Donna had to take early retirement on medical grounds. Donna had a severe limp, and had great difficulty getting up from her chair. She had to sit through the interview semi-reclining with her legs elevated as she is unable to sit upright or bend forwards and constantly repositioned herself throughout the interview.
Appendix F – Information Sheet

Participant Information Sheet

<table>
<thead>
<tr>
<th>Study title:</th>
<th>What is the experience of women who live with pelvic synthetic mesh complications?</th>
</tr>
</thead>
</table>

Introduction

Thank you for showing an interest in this project. Please read this information sheet carefully. Take time to consider and, if you wish, talk with relatives or friends, before deciding whether or not to participate.

If you decide to participate we thank you. We understand that your experience is very personal and if you decide not to take part we respect your decision.

What is the aim of this research project?

This research aims, through women’s stories, to respond to a gap identified in the literature in relation to the perceived quality of life of women experiencing pelvic mesh complications. The aim of the project is to reveal the impact and inter-relationship of mesh-related complications on the physical, psychological, social and spiritual domains of women’s lives.

The research is being conducted by a student investigator has personally experienced pelvic surgical mesh complications.

Findings from the project will have wide relevance to health professionals, pastoral caregivers, and regulators in terms of providing insights into the experience of living with pelvic mesh complications. The study will further develop knowledge in the area of person-centred care for women experiencing complications. It may also contribute to the conversation regarding future use of synthetic pelvic mesh for prolapse.

On December 11 2017 NZ regulator Medsafe introduced restrictions on surgical mesh, as a consequence of the Australian TGA (Therapeutic Goods Administration) review of surgical mesh for urogynaecological use. Further information can be found on the Medsafe website: http://www.medsafe.govt.nz/hot/alerts/UrogynaecologicalSurgicalMeshImplants.asp
Who is funding this project?

The student investigator's course fees are funded by Te Kotahitanga Trust, and funding to travel to interview participants has been provided by a grant from the Nursing Education and Research Foundation.

Who are we seeking to participate in the project?

We are seeking six women to participate in the project.

Participants will need to:

- be experiencing pelvic mesh complications
- have or have had implanted polypropylene mesh in the pelvic area (E.g. anterior, posterior, mid-urethral sling, sacrocolpopexy)
- have an accepted treatment injury claim lodged with ACC
- be sufficiently well mentally and physically to be able to participate in interviews

If you participate, what will you be asked to do?

Participate in:

- Completion of a questionnaire which helps assess changes in your life as a result of pelvic surgical mesh complications.
- One interview of around one hour. The interviews will be semi-structured and will last as long as the participant feels there is still more to tell. Regular breaks can be taken as needed by the participant. The researcher will travel to you.

Is there any risk of harm from participation?

Talking about and reflecting on your surgical mesh experience may give rise to raw emotions so participants are welcome to have a support person present during the interviews. The interviews will be conducted sensitively and can be stopped at any time. You will be asked if you are okay to continue at regular intervals during the interview.

What information will be collected, and how will it be used?

The interviews will be recorded using an electronic dictaphone. Once the research is published the electronic recordings will be deleted.

Any remaining data will be archived in secure storage at Otago University for five years after publication. A copy of the completed research paper will be provided to participants and they will be advised of any subsequent publications in journals.

What about anonymity and confidentiality?
Participants will be asked to choose a pseudonym for use in the final publication. No names, or other identifying details (age, occupation, or geographical location) will be used. All data will be filed on the researcher’s password protected laptop under the pseudonym chosen by the participant.

The interviews will be transcribed by the researcher. Once interviews are transcribed participants will be given the opportunity to review the transcript and remove any content that they may not be comfortable with.

**If you agree to participate, can you withdraw later?**

You may withdraw from participation in the project at any time and without any disadvantage to yourself. However once you have reviewed and approved the transcripts of your interviews the transcripts cannot be withdrawn.

**Any questions?**

If you have any questions now or in the future, please feel free to contact either:

<table>
<thead>
<tr>
<th>Name: Jacqueline Brown</th>
<th>Contact phone number:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Position: Masters Candidate/Student investigator</td>
<td>027 262 3901</td>
</tr>
<tr>
<td>Department: Theology and Religion</td>
<td>03 543 2165</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Name: Murray Rae</th>
<th>Contact phone number:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Position: Principal Investigator</td>
<td>021 074 7088</td>
</tr>
<tr>
<td>Department: Theology and Religion</td>
<td></td>
</tr>
</tbody>
</table>

*This study has been approved by the University of Otago Human Ethics Committee (Health). If you have any concerns about the ethical conduct of the research you may contact the Committee through the Human Ethics Committee Administrator (phone +64 3 479 8256 or email gary.witte@otago.ac.nz). Any issues you raise will be treated in confidence and investigated and you will be informed of the outcome.*
All meshed up – surviving a

A nurse tells of her seven-year struggle following implantation of vaginal mesh for a recurring cystocele.

By Jacqueline Brown

I’ve got mesh, you can feel it all the time,” said the nurse helping me into my gown, moments before I was taken to the operating theatre. There I was to have American Medical Systems Prolene transvaginal mesh implanted into the anterior wall of my vagina for recurrent cystocele. That was in 2010. The nurse’s off-the-cuff comment was just a hint of the seven-year journey to come.

Before the surgery, the gynaecologist at a specialist clinic told me he would insert a small piece of mesh in the anterior wall and I would not need to worry about prolapse again - it would be a “lifeline fix”. I was informed there was a “small risk” of erosion and that, once implanted, it would be difficult to remove. I was not told the small piece of mesh had four arms attached and that these are inserted through the obturator muscles using stainless steel trochars that wouldn’t birk amiss in the garden section of a hardware store. The arms are then tensioned before being cut and allowed to withdraw into the tissues.

Inadequate informed consent
Inadequate informed consent is common. The American College of Obstetricians and Gynaecologists ethical guidelines state “... without adequate data on the risks and benefits of new treatments, patients are unable to provide a true informed consent.” American gynaeoncologist and author Donald Osberg on gives a step further and says without safety and efficacy data, a new treatment can only be considered experimental. This, he says, is because no Level 1 studies were done on the use of surgical mesh for pelvic organ prolapse before its introduction to the market. The United States Food and Drug Administration (FDA) cleared new transvaginal devices based on “substantial equivalence” to previously cleared mesh devices for hernias, without requiring supporting clinical data.

Up until now, New Zealand regulator Medsafe has simply recognised the approvals of other regulators, such as the FDA.

After the surgery, I could feel the mesh in situ, although it wasn’t painful, at least initially. Having had endometriosis for many years before a hysterectomy in 2008, I was familiar with vague pelvic aches and pains, so the constant low-level discomfort was a small price to pay for “a lifeline fix.” I had my bike adjusted so I could ride it comfortably. I was careful sitting down to avoid the sudden painful pulling sensation in my right groin, and I experienced the occasional sharp electric pain which travelled up the vagina at random. I had difficulty standing for long at my children’s school events. After prolonged physical activity, I would often lie down until the strained feeling passed. These often turned into naps, as I frequently felt fatigued. I adjusted my life around the mesh.

In March 2014, as a result of Charlotte Korte and Carmel Barry’s petition to the Parliamentary Health Select Committee, the media carried several articles about the detrimental effects of transvaginal mesh. I began to realise that what I was living with was not normal. I started researching the effect of polypropylene mesh in the body. I found it is not inert and is prone to contraction beyond the 20-30 per cent anticipated. It is subject to infection due to contamination on insertion via the vagina, the development of bacterial biofilms around the mesh, and chronic inflammatory response to the foreign body. For these reasons, mesh implantation is contraindicated in patients with autoimmune tendencies. I had a history of both endometriols and acne sarcodentes.

Other studies have shown the mesh itself starts to degrade and become brittle. Nerves and blood vessels grow through the pores in the mesh, causing pain when the mesh contracts. The ideal biomaterial for permanent implantation is yet to be discovered.

Around this time, class action suits were being taken against American Medical Systems in the United States (US), the manufacturer of Prolene meshes. The company eventually paid out US$1.4 billion to 20,000 claimants, and there are more than 4000 claims still to settle. Claims against other manufacturers are occurring worldwide.

I returned to the gynaecologist who implanted my mesh, naively thinking he put it in, so he should know how to take it out. He identified the mesh had failed and this was causing tension in the tissues. He referred me to a urologist and they both recommended a two-stage process – removal of the mesh, followed by a second operation, sacrocolpopexy. This involves attaching mesh to the sides of the vaginal vault which is then sus-
a surgical mesh implant

...ended from the sacrospinous ligament. I struggled to comprehend how implanting more mesh could be beneficial, given the problems I was experiencing with the mesh I already had. After seeking a second opinion, I decided to proceed with the mesh removal only.

A treatment injury

I had not realised my situation was considered a treatment injury and had started the process using Southern Cross. The urologist later submitted a treatment injury claim on my behalf. This was the beginning of months of to-ing and fro-ing with the Accident Compensation Corporation (ACC). ACC did not accept my symptoms as "injury" and the surgeon had to submit letters saying the injury was mesh related. This link is often difficult to prove without advanced radiological scanning or surgery.

In Australia, one commentator says the "mesh scandal" exposes how the burden of proof and responsibility for raising serious health issues is left with "the patient who is dismissed in the first place" while regulators often remain in denial.

A recent report by the Legal Issues Centre at Otago University highlighted the often obstructive and legalistic approach adopted by ACC to treatment injury claims, which I am told adds to mesh-related women's distress.

In August 2014, I underwent surgery to remove the mesh. Post-operatively, I was told the surgeons had "got it all." Reading the operation note several weeks after the surgery, it became clear they had not got it all. They had dissected the uterus back to bone and ligament and cut them, leaving what they estimated was 1-2cm of all four mesh areas in the tissues. They observed that the mesh had contracted by two thirds. Research on mesh use in cystocele repair shows vaginal mesh can contract by 10 per cent a year and up to 85 per cent at eight years. The fibrous scar tissue around the mesh also contracts, causing the mesh to bunch up. Despite my pre-operative request, the explanted mesh was not sent to the lab. No photographs were taken. I was told this was because they were unable to see the mesh as it was in tissue. My post-operative pain was managed poorly. I had significant bleeding and was discharged early as the hospital wanted to close the ward for the weekend.

Meanwhile, I awaited ACC's treatment injury approval. The bleeding continued and two weeks after the initial surgery, I returned to theatre in a public hospital to have the bleeding stopped. Over the following weeks, I had urine infections which required several courses of antibiotics. I was unable to work and, as the treatment injury claim is tied up, I transferred my $78,54 debt to a debt collection agency. During my recovery, I was harassed almost daily by this agency. I also received letters from the hospital threatening to register the debt with Baycorp. Thankfully, they were more understanding of my situation. Finally, ACC paid out and, I received some money for lost income. Our heads were barely above water by Christmas and I was exhausted physically and mentally when I finally returned to work as a nurse for Healthline.

In January 2015, I started experiencing episodes of severe pain. I was confused - if the mesh and most of the arms had been removed, then what could be causing the pain? There was no offensive discharge and I was tested for bacterial vaginosis on multiple occasions but found to be clear. Through trial and error I found that Zoloft vaginal gel (Mecenil) relieved the pain. This relief would last about 10 days after completion of the course before I needed further gel. I saw a gynaecologist who could find nothing of significance. Local anaesthetic injections to the vaginal vault temporarily relieved the pain, but it returned within hours. The gynaecologist tried to map out the painful area and considered removing the area of painful tissue, in case remaining mesh fibres were causing the pain. However, on each visit the pain seemed to be located somewhere different. I had started a new job and couldn’t face another surgery. I felt like a hypochondriac. My husband was tired of hearing me say "I just don’t feel right," I wondered if the GP thought I was making more of things than the evidence supported, and I started to second guess myself.

I gained some relief from a herb with anti-inflammatory and anti-oxidative...
The urogynaecologist said the explanted mesh felt like barbed wire.

While it is important to measure the anatomical success of a surgery, the biggest gap in many of these studies is the long-term measurement of women's post-mesh quality of life — their lived experience.

The failure rate of traditional transvaginal mesh repair ranges from seven to 70 per cent, depending on what you read. Although transvaginal mesh repair with mesh has higher anatomical longevity, it also has more complications. This begs the question: how many mesh-injured women is too many?

Mesh complications adversely and often permanently affect every area of a woman's life — relationships, sexuality, work, whakaua and physical, spiritual and emotional health.

The Royal Australian and New Zealand College of Obstetricians and Gynaecologists position statement on vaginal mesh does not recommend it as a first-line treatment. Two Australian urogynaecologists say 70 per cent of women with mesh complications have had it explanted.

The Australian and New Zealand College of Obstetricians and Gynaecologists position statement on vaginal mesh does not recommend it as a first-line treatment. Two Australian urogynaecologists say 70 per cent of women with mesh complications have had it explanted.
Primary health care: Celebrating 30 years

NEWTOWN UNION Health Service (NUHS) celebrated its 30-year anniversary last month. For the very low cost access (LICA) practice, which serves high-needs populations in the Wellington South area, it’s been a 30-year story of struggle and survival, but also of great success. NUHS cares for more than 6500 patients, about a quarter from Pacific communities, while 15 per cent identify as Māori, 18 per cent as European and 17 per cent as Asian. Twenty-six per cent come from other ethnicities, including refugees and migrants who are a significant part of its involved population.

Speaking after the celebration, board chair and NUHS president Grant Brookes said NUHS was determined to survive and to continue caring for its community. He said the day had been “amazing”, with former staff, patients, board chairs and the community present. “It was a real eye-opener and very moving for me to witness how much the NUHS means to our communities. People expressed gratitude for the life-saving care they had received from our service.”

Long-serving NUHS nurse Bryony Halls joins in at the celebrations.

NUHS is celebrating its 30th year. NUHS to make sure this new model of care works in patients’ best interests.”

Brookes said.

Report by co-editor Anne Manchester

All meshed up — surviving a surgical mesh implant (pp20-22) — references


Appendix H – The amended ICIQ-LUTSqol Questionnaire

Quality of life

Below are some daily activities that can be affected by urinary problems. How much does your mesh problem affect you? We would like you to answer every question, Simply tick the box that applies to you.

We would be grateful if you could answer the following questions, thinking about how you have been, on average, over the past four weeks.

1. Please write in your date of birth:

   DAY  MONTH  YEAR

2. Are you (tick one):

   Female  Male

3a. To what extent does your mesh problem affect your household tasks (e.g. cleaning, shopping, etc.)

   not at all  1
   slightly    2
   moderately  3
   a lot       4

3b. How much does this bother you?

   Please ring a number between 0 (not at all) and 10 (a great deal)

   0  1  2  3  4  5  6  7  8  9  10
   not at all  a great deal

4a. Does your mesh problem affect your job, or your normal daily activities outside the home?

   not at all  1
   slightly    2
   moderately  3
   a lot       4

4b. How much does this bother you?

   Please ring a number between 0 (not at all) and 10 (a great deal)

   0  1  2  3  4  5  6  7  8  9  10
   not at all  a great deal

Copyright © "ICIQ Group"; the ICIQ-LUTSqol is based on the King's Health Questionnaire
5a. Does your mesh problem affect your physical activities (e.g. going for a walk, run, sport, gym, etc.)?
   - not at all □ 1
   - slightly □ 2
   - moderately □ 3
   - a lot □ 4

5b. How much does this bother you?
   Please ring a number between 0 (not at all) and 10 (a great deal)
   0 1 2 3 4 5 6 7 8 9 10
   not at all a great deal

6a. Does your mesh problem affect your ability to travel?
   - not at all □ 1
   - slightly □ 2
   - moderately □ 3
   - a lot □ 4

6b. How much does this bother you?
   Please ring a number between 0 (not at all) and 10 (a great deal)
   0 1 2 3 4 5 6 7 8 9 10
   not at all a great deal

7a. Does your mesh problem limit your social life?
   - not at all □ 1
   - slightly □ 2
   - moderately □ 3
   - a lot □ 4

7b. How much does this bother you?
   Please ring a number between 0 (not at all) and 10 (a great deal)
   0 1 2 3 4 5 6 7 8 9 10
   not at all a great deal

8a. Does your mesh problem limit your ability to see/visit friends?
   - not at all □ 1
   - slightly □ 2
   - moderately □ 3
   - a lot □ 4

8b. How much does this bother you?
   Please ring a number between 0 (not at all) and 10 (a great deal)
   0 1 2 3 4 5 6 7 8 9 10
   not at all a great deal

Copyright © "ICIQ Group": the ICIQ-LUTSql is based on the King’s Health Questionnaire
9a. Does your mesh problem affect your relationship with your partner?

- not applicable [ ]
- not at all [ ]
- slightly [ ]
- moderately [ ]
- a lot [ ]

9b. How much does this bother you?

*Please ring a number between 0 (not at all) and 10 (a great deal)*

<table>
<thead>
<tr>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
</tr>
</thead>
<tbody>
<tr>
<td>not at all</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>a great deal</td>
</tr>
</tbody>
</table>

10a. Does your mesh problem affect your sex life?

- not applicable [ ]
- not at all [ ]
- slightly [ ]
- moderately [ ]
- a lot [ ]

10b. How much does this bother you?

*Please ring a number between 0 (not at all) and 10 (a great deal)*

<table>
<thead>
<tr>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
</tr>
</thead>
<tbody>
<tr>
<td>not at all</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>a great deal</td>
</tr>
</tbody>
</table>

11a. Does your mesh problem affect your family life?

- not applicable [ ]
- not at all [ ]
- slightly [ ]
- moderately [ ]
- a lot [ ]

11b. How much does this bother you?

*Please ring a number between 0 (not at all) and 10 (a great deal)*

<table>
<thead>
<tr>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
</tr>
</thead>
<tbody>
<tr>
<td>not at all</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>a great deal</td>
</tr>
</tbody>
</table>

12a. Does your mesh problem make you feel depressed?

- not at all [ ]
- slightly [ ]
- moderately [ ]
- very much [ ]

12b. How much does this bother you?

*Please ring a number between 0 (not at all) and 10 (a great deal)*

<table>
<thead>
<tr>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
</tr>
</thead>
<tbody>
<tr>
<td>not at all</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>a great deal</td>
</tr>
</tbody>
</table>

Copyright © "ICIQ Group"; the ICIQ-LUTSqol is based on the King's Health Questionnaire
13a. Does your mesh problem make you feel anxious or nervous?

- Not at all: 1
- Slightly: 2
- Moderately: 3
- Very much: 4

13b. How much does this bother you?

*Please ring a number between 0 (not at all) and 10 (a great deal)*

<table>
<thead>
<tr>
<th>Number</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>Not at all</td>
</tr>
<tr>
<td>1</td>
<td>Slightly</td>
</tr>
<tr>
<td>2</td>
<td>Moderately</td>
</tr>
<tr>
<td>3</td>
<td>Very much</td>
</tr>
</tbody>
</table>

14a. Does your mesh problem make you feel bad about yourself?

- Not at all: 1
- Slightly: 2
- Moderately: 3
- Very much: 4

14b. How much does this bother you?

*Please ring a number between 0 (not at all) and 10 (a great deal)*

<table>
<thead>
<tr>
<th>Number</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>Not at all</td>
</tr>
<tr>
<td>1</td>
<td>Slightly</td>
</tr>
<tr>
<td>2</td>
<td>Moderately</td>
</tr>
<tr>
<td>3</td>
<td>Very much</td>
</tr>
</tbody>
</table>

15a. Does your mesh problem affect your sleep?

- Never: 1
- Sometimes: 2
- Often: 3
- All the time: 4

15b. How much does this bother you?

*Please ring a number between 0 (not at all) and 10 (a great deal)*

<table>
<thead>
<tr>
<th>Number</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>Not at all</td>
</tr>
<tr>
<td>1</td>
<td>Slightly</td>
</tr>
<tr>
<td>2</td>
<td>Moderately</td>
</tr>
<tr>
<td>3</td>
<td>Very much</td>
</tr>
</tbody>
</table>

16a. Do you feel worn out/tired?

- Never: 1
- Sometimes: 2
- Often: 3
- All the time: 4

16b. How much does this bother you?

*Please ring a number between 0 (not at all) and 10 (a great deal)*

<table>
<thead>
<tr>
<th>Number</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>Not at all</td>
</tr>
<tr>
<td>1</td>
<td>Slightly</td>
</tr>
<tr>
<td>2</td>
<td>Moderately</td>
</tr>
<tr>
<td>3</td>
<td>Very much</td>
</tr>
</tbody>
</table>

Copyright © "ICIQ Group": the ICIQ-LUTSqol is based on the King's Health Questionnaire.
Do you do any of the following? If so, how much?

17a. Wear pads to keep dry?

   never ☐ 1
   sometimes ☐ 2
   often ☐ 3
   all the time ☐ 4

17b. How much does this bother you?

   Please ring a number between 0 (not at all) and 10 (a great deal)

   0 1 2 3 4 5 6 7 8 9 10
   not at all a great deal

18a. Be careful how much fluid you drink?

   never ☐ 1
   sometimes ☐ 2
   often ☐ 3
   all the time ☐ 4

18b. How much does this bother you?

   Please ring a number between 0 (not at all) and 10 (a great deal)

   0 1 2 3 4 5 6 7 8 9 10
   not at all a great deal

19a. Change your underclothes when they get wet?

   never ☐ 1
   sometimes ☐ 2
   often ☐ 3
   all the time ☐ 4

19b. How much does this bother you?

   Please ring a number between 0 (not at all) and 10 (a great deal)

   0 1 2 3 4 5 6 7 8 9 10
   not at all a great deal

20a. Worry in case you smell?

   never ☐ 1
   sometimes ☐ 2
   often ☐ 3
   all the time ☐ 4

20b. How much does this bother you?

   Please ring a number between 0 (not at all) and 10 (a great deal)

   0 1 2 3 4 5 6 7 8 9 10
   not at all a great deal
### 21a. Get embarrassed because of your mesh problem?

<table>
<thead>
<tr>
<th>never</th>
<th>sometimes</th>
<th>often</th>
<th>all the time</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>

### 21b. How much does this bother you?

*Please ring a number between 0 (not at all) and 10 (a great deal)*

<table>
<thead>
<tr>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
</tr>
</thead>
<tbody>
<tr>
<td>not at all</td>
<td>a great deal</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### 22. Overall, how much do mesh symptoms interfere with your everyday life?

*Please ring a number between 0 (not at all) and 10 (a great deal)*

<table>
<thead>
<tr>
<th>0</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
</tr>
</thead>
<tbody>
<tr>
<td>not at all</td>
<td>a great deal</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

---

Copyright © "ICIQ Group" : the ICIQ-LUTSsqol is based on the King’s Health Questionnaire
Appendix I - Additional Global Spiritual Question

For some people, their religious or spiritual beliefs act as a source of comfort and strength in dealing with life’s ups and downs; what has been your experience?

Please ring a number between 0 (has not helped at all) and 10 (has helped a great deal)

<table>
<thead>
<tr>
<th>Has not helped at all</th>
<th>Has helped a great deal</th>
</tr>
</thead>
<tbody>
<tr>
<td>0 1 2 3 4 5 6 7 8 9 10</td>
<td></td>
</tr>
</tbody>
</table>
Appendix J – Interview Schedule

INTERVIEW SCHEDULE and Script

Thank you for allowing me to interview you today. This should take about an hour.

The purpose of this interview is for you to be able to tell your story of living with pelvic surgical mesh complications.

I may ask a small number of questions based on areas of your life that you have identified as affected in the questionnaire that you completed.

If at any time during the interview you would like to stop for any reason please say so.

Key Question:

- Describe your experience of living with mesh complications...

Sub Questions

- Describe your life before your mesh surgery...
- How has this experience affected your sense of yourself as a woman?
- What impact has this experience had on your roles provider/ mother/ daughter/ sister/ lover..? (as appropriate)
- How has this experience affected your life plans?
- What are your sources of hope, strength, comfort and peace? OR What sustains you and keeps you going?

Specific Questions relating to ICIQ

If interviewee has not specifically covered items identified in their ICIQ questionnaire in their narrative then ask about these.

In your responses to the questionnaire you were asked to complete you identified [x] areas where mesh complications impacted on your life especially. Tell me more about...

<table>
<thead>
<tr>
<th>Area</th>
<th>Tick</th>
<th>Area</th>
<th>Tick</th>
</tr>
</thead>
<tbody>
<tr>
<td>Household tasks</td>
<td></td>
<td>Sex life</td>
<td></td>
</tr>
<tr>
<td>Job/normal daily activities outside the home</td>
<td></td>
<td>Family</td>
<td></td>
</tr>
<tr>
<td>Physical activities</td>
<td>Depressed</td>
<td></td>
<td></td>
</tr>
<tr>
<td>-------------------------</td>
<td>----------------------------------</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Ability to travel</td>
<td>Anxious or nervous</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Social life</td>
<td>Feel bad about yourself</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Ability to see/visit friends</td>
<td>Sleep</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Relationship with partner</td>
<td>Worn out/tired</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

+/− Response to global spiritual question ☐

**Closing**

Thank you for sharing your story with me today.

What will happen now is that I will transcribe the recording I have made today, and add in any notes. In the next few weeks I will send you the transcript to review and approve. If you are unhappy with anything you have said it can be removed.

The interview may have stirred up some raw emotions so be kind to yourself for the rest of the day and talk to the people who usually support you.

If you feel that you need to talk with someone in a formal capacity you may be able to access free counselling sessions through your GP, or ACC.

If you have any concerns or questions about the study, or our interview today please call me, or my supervisor, our numbers are on the information sheet.
## Appendix K – Glossary

<table>
<thead>
<tr>
<th>Term</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Anterior</strong></td>
<td>Front, in this context the front wall of the vagina. The bladder is found on the other side of this wall.</td>
</tr>
<tr>
<td><strong>Biological graft</strong></td>
<td>Where tissue is harvested from the woman herself (autograft), a cadaver (allograft), or animals such as pigs (xenograft), processed, sterilised and implanted to support prolapsing tissues.</td>
</tr>
<tr>
<td><strong>Bovine</strong></td>
<td>Originating from cattle.</td>
</tr>
<tr>
<td><strong>Clitoris</strong></td>
<td>Sensitive part of the female sex organs.</td>
</tr>
<tr>
<td><strong>Colonoscopy</strong></td>
<td>A long flexible tube with a camera at the tip called a colonoscope is used to visualise the inside of the colon to check for abnormality.</td>
</tr>
<tr>
<td><strong>Colostomy</strong></td>
<td>Where one end of the colon is brought out to the abdominal wall, forming a stoma, to which a bag is attached to collect faeces.</td>
</tr>
<tr>
<td><strong>Cystocele</strong></td>
<td>Where the bladder bulges into the vagina.</td>
</tr>
<tr>
<td><strong>Cystoscopy</strong></td>
<td>A rigid or flexible tube with a camera is introduced through the urethra into the bladder so that the interior of the bladder can be visualised.</td>
</tr>
<tr>
<td><strong>De novo</strong></td>
<td>“Of new” or “Anew.”</td>
</tr>
<tr>
<td><strong>Dyspareunia</strong></td>
<td>Pain during sexual intercourse.</td>
</tr>
<tr>
<td><strong>Erosion</strong></td>
<td>Specific to mesh – the mesh wears through the tissue becoming exposed. Also called exposure, extrusion or protrusion.</td>
</tr>
<tr>
<td><strong>Femoral artery</strong></td>
<td>A large artery in the thigh, and the main artery supplying the leg.</td>
</tr>
<tr>
<td><strong>FDA</strong></td>
<td>The United States Food and Drug Administration.</td>
</tr>
<tr>
<td><strong>Granuloma tissue</strong></td>
<td>New connective tissue that forms on a wound during the healing process.</td>
</tr>
<tr>
<td><strong>Gynaecologist</strong></td>
<td>A practitioner of the medical specialty dealing with the female reproductive system (primarily the vagina, ovaries, uterus).</td>
</tr>
<tr>
<td>Term</td>
<td>Description</td>
</tr>
<tr>
<td>--------------------------</td>
<td>-----------------------------------------------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Haemorrhoids</td>
<td>Painful, swollen veins near the anus.</td>
</tr>
<tr>
<td>Ischium</td>
<td>The lower, back part of the hip bone.</td>
</tr>
<tr>
<td>Kiwisaver</td>
<td>A voluntary, work-based savings scheme for retirement.</td>
</tr>
<tr>
<td>Medsafe</td>
<td>New Zealand Medicines and Medical Devices Safety Authority. Regulates medicines and medical devices.</td>
</tr>
<tr>
<td>Mesh</td>
<td>Also referred to as tape, sling.</td>
</tr>
<tr>
<td>Mesh kits</td>
<td>Single use, disposable kits containing all the components required to implant mesh.</td>
</tr>
<tr>
<td>Native tissue</td>
<td>Similar to Biological graft, where tissue from the woman’s body is harvested at the time of the surgery and used to support prolapsed organs.  This usually involves using rectus fascial tissue from the abdominal wall to form a sling.</td>
</tr>
<tr>
<td>Obturator</td>
<td>The muscle covering the outer front part of the pelvis on each side. These muscles help to move the thigh and hip.</td>
</tr>
<tr>
<td>Polypropylene</td>
<td>A thermoplastic polymer - a plastic.</td>
</tr>
<tr>
<td>POP</td>
<td>Pelvic Organ Prolapse.</td>
</tr>
<tr>
<td>Posterior</td>
<td>Behind. In this context the back wall of the vagina, on the other side of the wall sits the rectum.</td>
</tr>
<tr>
<td>Psychogenic</td>
<td>Originating in the mind.</td>
</tr>
<tr>
<td>Rectocele</td>
<td>Where the rectum bulges into the vagina.</td>
</tr>
<tr>
<td>Sacrospinus ligament</td>
<td>A small ligament in the pelvis. The base of the ligament is attached to the outer edge of the sacrum and coccyx, and the tip of the ligament attaches to the spine of the ischium, a bone in the human pelvis. This ligament is often used to suspend mesh in the pelvis.</td>
</tr>
<tr>
<td>SUI</td>
<td>Stress Urinary Incontinence.</td>
</tr>
<tr>
<td>Suprapubic cathether</td>
<td>A catheter passed through the abdominal wall into the bladder. These are commonly used for long term catheterisation.</td>
</tr>
<tr>
<td>Tape division</td>
<td>Cutting the mesh tape under the urethra, or partial removal of a portion of the tape as a form of conservative management</td>
</tr>
</tbody>
</table>
with the aim of resolving problems with voiding, pain, or erosion.

**TVT**
Trans Vaginal Tape. A mesh sling inserted through an incision in the vagina to support the bladder neck.

**Ureter**
One of two tubes, one from each kidney to the bladder.

**Urethra**
The tube from the bladder through which one passes urine.

**Urologist**
A practitioner of the medical specialty dealing with the urinary system (kidneys, ureters, bladder, urethra).

**Urogynaecologist**
A medical practitioner who deals with the urinary system and the female reproductive system.

**510k process**
A process of premarket submission to the FDA to demonstrate that the device to be marketed is at least as safe and effective, that is, substantially equivalent, to a legally marketed device that is not subject to premarket approval.