Surgical mesh complications – a study in pain, loss and isolation

Complications of surgical mesh implants have radically altered the lives of many New Zealand women. Two recent research studies reveal the extent of these women’s struggles.

By co-editor Teresa O’Connor

Two recently-released New Zealand qualitative research studies into the impact of surgical mesh complications on women’s lives paint a grim picture of chronic pain, loss, grief, isolation and a constant battle to be heard by health professionals, the wider health system and the Accident Compensation Corporation (ACC).1,2 Both were conducted by nurses.

Jacqueline Brown, who herself endured debilitating surgical mesh complications, completed a thesis, A Thorn in the Flesh: The experience of women living with pelvic surgical mesh complications, for her master of chaplaincy through Otago University last year. She interviewed seven women, aged between 43 and 69, all of whom had an ACC treatment injury claim, and describes their stories as “illness narratives”.

The other study, The Loss of a Life Well Lived, was commissioned by the Mesh Down Under (MDU) support group and undertaken by Massey University nursing professor Annette Huntington, research assistant Emma Bramwell and MDU health advocate Patricia Sullivan and published in April. Twenty-three self-selected women, aged from 30 to 69, shared their experiences. The average length of time the women had lived with surgical mesh was nine years.

Both studies revealed how the women’s lives were dramatically altered because of the mesh implants, used to treat either pelvic organ prolapse, stress urinary incontinence or both.

Seven themes identified

Brown identified seven themes from the women’s stories: feeling powerless in the medical space; living in a shrinking world; living with unrelenting pain; inhabiting a body that could no longer be relied on; living in the gap between what was and what could have been; suffering in silence; and finding “absolute other” and others as a source of strength.1

Isolation a recurrent theme

Physical, emotional and social isolation was a recurrent theme of the women’s stories in both studies. Pain intensity and incontinence restricted women’s ability to work, volunteer, socialise and travel. This “shrinking” of their worlds happened at both a physical and social level, Huntington reported.

Brown’s research demonstrated that the impact of mesh complications were far wider than just emotional or psychological – “it reaches the furthest boundaries of the women’s lifeworlds”.1

Women experienced a world that was shrinking, with the loss of personal and professional roles, social isolation, limited ability to travel, and limited resources. Their previously expansive worlds had contracted, according to Brown’s research. One spoke of how her world had shrunk to a “10-minute radius of home”.1

A participant in Huntington’s study explained that shrinking world. “The biggest impact has been a loss of physical activity in every area of my life, including ability to garden and do housework, Pilates, hiking, swimming, walking running, yoga, exercise, sex and a loss of confidence and a resultant loss of social life.”2

Another, in Brown’s study, said she felt her life had “been shredded and left hanging in a whole lot of pieces. The problems caused by mesh for me have almost felt like a life sentence of home detention, it has been so isolating. ‘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 have almost felt like a life sentence of home detention, it has been so isolating.’

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of the unrelenting pain and distress of their complications.

Chronic pain and incontinence meant many of the women either reduced their working hours or lost their jobs. Of the 22 who mentioned work in Huntington’s study, only three had been able to continue working as normal and 15 had to stop work completely. Less or no work had financial consequences and also affected the women’s relationships, self-esteem and sense of fulfilment. 

Post-mesh reality

In Brown’s study, six of the women were working before having mesh implants and one was studying. All participants were fit, healthy and independent before the mesh implantation, but their post-mesh reality was significantly different. Some had struggled to find their value again due to the limitations imposed by the mesh complications and by being unable to do what they had done previously.

Thirteen of the women in Huntington’s study discussed how their mesh injury negatively affected their ability to interact with and care for their children and/or grandchildren. As one woman explained: “The hardest impact is knowing that even though it is hard on me, it is much harder for my children. They miss out on a lot. We have to ‘manage’ what we do as a family because I am unable to join in.”

Three of the women in Brown’s study were grandparents and shared their frustrations at not being able to interact with their grandchildren as they wanted to.

Some commented on the difficulty their families had in understanding their pain and this affected family relationships and exacerbated the women’s sense of isolation.

One of the women in Brown’s study said her situation had affected the wider family and caused loss of relationships, leaving her feeling isolated and alone. “It has been quite difficult as I have been rejected and judged by some family members... Apart from one cousin, the rest [family members] don’t have anything to do with me; it’s like I don’t exist, to them I have no life so am not worth knowing.”

These findings echo those of the report of the Australian Senate Inquiry into the impact of transvaginal mesh implants, which referred to the deterioration of relationships with family and friends and how this left women lonely.

Pain meant intimate relationships were profoundly affected for women in both studies. In Huntington’s study, 11 of the 18 women in relationships said their sex life had stopped completely due to their injury, with another three saying their sex life had been seriously impacted. Women in both studies also said their partners had been injured by the mesh during sex.

In both studies, some of the women not in relationships said their injuries had affected their confidence in their ability to meet prospective partners and begin new relationships.

Many of the women spoke about the lack of informed consent for the surgical procedures and their anger at not being heard or believed by the medical profession and ACC. A number said that before surgery, they had not been made aware of potential complications from the mesh implants. Several said they had trusted the surgeon recommending the procedure.

**SOME FACTS AND FIGURES ON SURGICAL MESH**

- **Mesh** is a loosely woven sheet of biological and inorganic materials.
- **It has been used to treat a number of urogynaecological conditions including pelvic organ prolapse (POP) and stress urinary incontinence (SUI), since the 1990s.
- **In 2007**, a Cochrane review found insufficient evidence to support the safety of surgical mesh for POP.
- **In October 2008**, the United State Food and Drug Administration released a public health notification to alert clinicians to more than 1000 cases of adverse events related to transvaginal POP and SUI mesh.
- **The total number of surgeries using mesh for urogynaecological conditions in New Zealand is unknown, but an estimated 2200 surgeries for POP and SUI were carried out in 2018.**
- **There is little evidence of the long-term effects of mesh, particularly on quality of life and activities of daily living.**
- **From July 1, 2005** (when treatment-related injuries were first covered by ACC) to June 30, 2018, ACC received 1018 mesh-related claims; of these claims, 578 were due to POP or SUI surgeries, with ACC accepting 453 of these claims.
- **The number of claims during this 13-year period has been steadily increasing, with a 58 per cent increase in 2016/17 and an additional 34 per cent increase in 2017/18.**
- **In October 2018**, Australian Health Minister Greg Hunt apologised to Australian women affected by transvaginal mesh.
- **In December 2018**, the Government here asked women injured by mesh to register their interest in sharing their experiences to improve future patient safety.
because of their position and experience and, in some cases, the relationship they had built with that particular surgeon.

“The mesh was used on me by a trusted professional and I am furious that in 2013, with all the warning signs out there, he still recommended this as the best option for treating mild incontinence and a prolapse. This gynaecologist was the same guy I saw for 27 years. He had delivered one of my kids . . . There was a history of trust, for goodness sake,” one woman said.

One of the women in Brown’s study said her surgeon had implied that the surgery was the best option and said “that the mesh was inert, had been well researched, didn’t have any problems with shrinkage and things, and that there had been long-term studies done”.

Another questioned why she had agreed to surgery, “. . . but he was kind of 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”. Brown, in her thesis, said the lack of two-way communication and accurate information had left the women living a journey they would not have chosen, had they been presented with all the relevant information and options.

Struggle to be believed
Both studies found that once the women were experiencing the consequences of their implants, many struggled to get their surgeons, GPs and other medical professionals to believe their pain or the extent of the complications.

“This is the insidious nature of chronic pain and ill health, where your health professionals are constantly telling you that there is no basis for your pain and discomfort, and/or that it is highly, highly unlikely to have anything to do with your urogynaec surgery of implanted mesh devices – you end up not believing yourself,” one woman in Huntington’s study said.

Several women said their surgeons refused to accept the mesh was the cause of their symptoms, with one gynaecologist telling a woman her experiences post–surgery were normal and that she must be drinking too much. Another said she was made to feel like a “drug-seeking hypochondriac”.

One of the women in Brown’s research said she was not given the option of mesh removal, which may have improved her life. This had led to a grief borne of injustice, from the knowledge her complications did not need to happen and that they were ultimately preventable. Another concluded it was “all in my head” after a urologist declined a further cystoscopy to check if her symptoms were related to mesh.

Brown said that the effect of being told “there is nothing wrong with you”, regardless of how incapacitated the women were, could completely undermine women’s confidence in their lived experience and relationship to reality.

Ten of the 23 women in Huntington’s study mentioned struggles with ACC, with seven describing their interactions as a “fight” or a “battle”. This left some exhausted and, along with their mesh injury, had a severe impact on their day-to-day lives. The fight to prove their pain was related to the mesh implant or to get specific symptoms recognised as linked to their injury, led to extended interactions with ACC. One woman said it was a fight to get every new symptom covered, even though she was covered by ACC for a severe treatment injury.

In Brown’s research, only one of the women had a positive experience with ACC; and three had gone through multiple reviews. Two of the women talked of reviews being conducted in a motel unit, with the ACC representative on a microphone. “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.”

The Loss of a Life Well Lived report calls for the women to be heard and believed. “Rather than demeaning and blaming women, practitioners need to ensure they get the support and assistance they require,” the report said.

It made a number of recommendations, including the establishment of a register of women who have received surgical mesh implants; a review of practice and professional expectations, to ensure all practitioners who work with women believe their reality, work in partnership with them and meet patient-centred care requirements; a review of informed consent documentation, in partnership with women consumers, to ensure women are absolutely clear about the surgery and its pros and cons; financial support from ACC for mesh removal if this is the best way to alleviate symptoms; access to chronic pain management services; access to counselling; and ACC to put the woman, as the expert patient, at the centre of decision-making.

Wanting suffering acknowledged
In the summary of her thesis, Brown said the women she interviewed knew they would not get their pre-mesh lives back, but wanted all that they had suffered and lost to be acknowledged.

“They want to see the health and regulatory systems accept mesh complications as treatment-related, and to prevent other women suffering as they have,” Brown wrote.

References
There are concerning parallels between the treatment of women suffering complications from surgical mesh implants and the treatment of women with cervical cancer at Auckland’s National Women’s Hospital (NWH) decades earlier, according to researcher Jacqueline Brown.

Brown used the book *Doctors in Denial: The forgotten women in the ‘Unfortunate Experiment’*, as the basis for her comparisons. The treatment, or lack of it, for women with cervical cancer at NWH in the ‘60s, ‘70s and ‘80s came to light in 1987 and resulted in an inquiry led by Judge Silvia Cartwright and subsequent publication of the *Cartwright Report*. That report ultimately led to the establishment of the Office of the Health and Disability Commissioner (HDC) and the HDC Code of Consumer Rights.

The women with cervical cancer at NWH did not give consent to being part of what subsequently came to be known as the unfortunate experiment. Brown says some women in her research gave consent to the use of mesh, but it was not informed consent as outlined in the HDC Code of Rights. Others received mesh implants without giving consent.

At NWH, women were treated as objects, and Brown said some of the women in her study described feeling like “guinea pigs” and their stories reflected objectification of their genital area.

Other parallels include some survivors of both being left with scarred vaginas, making sex painful or impossible; and the role of the media in exposing women’s experiences in both situations.

Brown points out that the Royal Australian and New Zealand College of Obstetricians and Gynaecologists has been reluctant to apologise to New Zealand women about the use of surgical mesh implants, just as its predecessor had been reluctant to call a special meeting to discuss the *Cartwright Report*.

“There have been some major ethical failings in the care and treatment of mesh-injured women. I don’t think we have learnt from the Unfortunate Experiment.”

Massey University nursing professor Annette Huntington has found similarities between the findings of research into the impact of surgical mesh implants on women’s lives, and the findings of research conducted in 2004 into women with endometriosis, “deeply disturbing”.

She was involved in both research studies and said women in both were raising the same concerns about failure to be heard and believed. The two studies also revealed long delays for the women in getting any acknowledgement or resolution of their concerns.

“Why is that still happening, 15 years on? For some reason, in this specialty area [gynaecology] women have struggled to be believed and heard. All health professionals in the specialty really need to think about that,” Huntington said.

She asked why the women felt they had to fight to be taken seriously about something that had had such a cata-strophic impact on their lives. “Why did they have to work so hard for someone to believe them? Why did they have to constantly try and persuade people and institutions that they were experiencing something that was impacting so much on their day-to-day lives? We need to ask ourselves why that was the case. Is it because the way gynaecological services are structured is not supportive of women? Maybe there are wider issues around how public and private gynaecological services are structured. These issues beg further research.”

She noted the absence of a nursing presence in the stories of women affected by surgical mesh implants. “This is not a criticism of nursing but, from my point of view, there is little nursing research in relation to gynaecology per se, which is such a woman-centred specialty.”

Huntington praised the work of the support group Mesh Down Under (MDU) for its “tireless” work in bringing the issues to public attention and for their ongoing work to ensure women could give fully informed consent. She hopes the Ministry of Health’s restorative justice process for mesh-injured women, now underway, will help.

She urges mesh-injured women to be placed at the centre of all decision-making on the issue. “There is a current strong focus on patient-centred care in health. What does that really mean for this group of women?”

References