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"There's More to Care Than Just Healing From Incisions"

Examining the Health Care Experiences of Gynaecology Patients With a History of Trauma

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Abstract

This qualitative research study examined the health care experiences of fifteen gynaecology patients with a history of adverse life events, otherwise referred to as trauma, using a trauma-informed lens for analysis. The study was carried out in 2022 at the Royal Women's Hospital, Melbourne, Victoria, Australia. It was conducted in response to the researcher noticing that patients with a history of trauma often have distressing experiences whilst in hospital. The researcher wanted to better understand the needs of these patients, find out what improves their care experience and reduces distressing experiences from occurring.

The research study was approved by the Royal Women's Hospital Human Research Ethics Committee and promoted via posters and flyers across the hospital and externally to the Epworth Freemasons' Endometriosis Support Group. Fifteen semi-structured interviews were conducted, predominantly via Web Ex a video conferencing platform, and data were analysed using Braun and Clarke's Reflexive Thematic Analysis (Braun & Clarke, 2019).

The study findings contribute to the knowledge of the health care experiences of gynaecology patients with a history of trauma. To start with, most research participants, particularly those with endometriosis, had experienced recent or past distressing experiences whilst in hospital which shaped their expectations and behaviours when they attended hospital.

Moreover, there were many mediating factors which influenced the participants' care experience, including, the quality of the care relationship, the quality and integration of communication systems, the health care environment, and having support. Participants highly valued authenticity. They wanted acknowledged agency in their care and to have

clinicians check in on them and ask for their consent each step of their care journey. Genuine, acknowledging and validating care also mitigated the impact of distressing incidents as the participants felt seen and heard. Moreover, most participants did not think hospitals should undertake a trauma screen unless it is done properly and took active steps to help prevent traumatising events from occurring whilst in hospital through use of learnt coping skills and expertise.

While this is an exploratory study, the findings shows that gynaecology patients with a history of trauma, particularly those with endometriosis, are at high risk of having distressing health care experiences when in hospital. However, some aspects of the carer relationship improved the care experience of the participants and mitigated the impact of distressing incidents. These aspects of care align with trauma-informed principles and highlight the value of trauma-informed care. These findings also build on the existing trauma-informed care evidence base. Finally, while this patient group are at high risk of having distressing care experiences, they also actively use learnt skills and expertise to reduce the risk of re-traumatisation.

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Declaration

This is to certify that:

1. This thesis only comprises of my own original work towards the Master of Advanced Social Work.
2. Due acknowledgement has been made to all other materials used.
3. This thesis is fewer than 30,000 words in length, exclusive of tables, bibliography, and appendices.

Signed

Nicola Frances Wylie

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Several people have contributed to the development and completion of this research, and I wish to thank them enormously for their contribution. Firstly, I wish to acknowledge the land on which this research was conducted and pay my deepest respect to the Wurundjeri and Boon Wurrung people, their elders past, present and emerging.

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Chapter 1: Introduction

1.1 Establishing the Context

This study draws on the lived experience of the researcher's role as a social worker at the Royal Women Hospital (RWH) where the researcher provides support to patients with gynaecological conditions. RWH is a tertiary hospital in Melbourne which provides specialist healthcare to women or people assigned female at birth (AFAB). Healthcare services offered at RWH include antenatal and neonatal care, abortion and contraception services, gynaecology services, sexual health, and oncology services.

Gynaecological conditions treated at RWH include endometriosis, chronic pelvic pain, incontinence, heavy menstrual bleeding, and pelvic floor conditions. Different forms of treatment are offered including surgical and pain management of these conditions. Some patients are admitted for planned treatment, while others have unplanned or emergency admissions into hospital[1].

Many gynaecology patients only receive treatment within the outpatient health care setting; however, many are assessed as being suitable for surgical treatment of their condition. If a patient is assessed as being suitable for surgical treatment, they are reviewed within the preadmission clinic and waitlisted for surgery. Whilst some gynaecology patients come into hospital for day surgery, others who have more significant surgical treatments, are admitted to the Ward 5 North for an inpatient stay.

The role of the gynaecology social worker at the hospital is complex and varied and the reasons patients are referred for social work support are numerous. Patients might be referred if they are experiencing family violence, or because concerns have

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[1] The Royal Women's Hospital (thewomens.org.au)

been identified about the safety or wellbeing of children in their care; They may also be referred because they have experienced an early pregnancy loss, or if they need advocacy support in relation to their health care needs. Some patients come into hospital through emergency, and may require crisis support, while others who have planned surgery, may need support to ensure their safe and prompt discharge from hospital.

The role of the gynaecology social worker at RWH is unique because both outpatients and inpatients are supported. Patients who are due to have surgery may be referred to social work, especially if there are discharge planning barriers identified in advance. The gynaecology social worker works outside the various clinics and wards and has a critical role in ensuring information about patients' particular care needs is communicated to the teams involved at each stage of their care journey. This is particularly important if the patient has complex psychosocial needs which might impact on both their health care experience and their safe discharge.

1.2 Stating the Problem

It was while working on the hospital ward that the researcher noticed that some inpatients with a gynaecological condition were being referred to social work for emotional support after having experienced a distressing incident (also known as a "triggering" or "re-traumatising" incident) during their inpatient stay.

These patients often disclosed a history of traumatic or painful life events (for the sake of conciseness, the term "history of trauma" is used throughout this thesis and the term "trauma" refers to psychological not medical trauma). Examples of traumatic life events include sexual assault, being a survivor of child abuse including physical, emotional, or sexual abuse or being a survivor or witness to family violence.

Sometimes the care team was already aware of the patient's history of trauma prior to their hospital admission, however, at other times, it was not. At times, the researcher had to spend additional time with these patients, providing them with emotional support and assisting them to address their needs and concerns. Mary's case study is set out below to illustrate this problem.

Case Study

Mary[2] was referred to social work for emotional support after she became distressed and had a panic attack during a gynaecological procedure. She disclosed that one of the doctor's touched her head without telling her that he was about to do this. She also disclosed that she had been sexually abused during her childhood and that the doctor reminded her of the perpetrator of the abuse. Using breathing techniques, the nursing staff were able to help her overcome her panic attack, and she was able to continue with the procedure; however, since this incident occurred, she reports being scared to have any further procedures in case the same thing happens again.

The researcher wanted to find out what could be done to improve the care of patients such as Mary and prevent distressing experiences from occurring, so met with senior nursing staff to discuss ways to do this. It was through these discussions that the idea of completing a study aimed at improving the health care experiences of gynaecology patients with a history of distressing life events first emerged.

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[2] *Mary's name and some details have been changed to protect her identity.*

1.3 Study Rationale

To establish a rationale for conducting the study the researcher conducted a literature review. The aim of this was to see if there is any existing evidence supporting the assumption that gynaecology patients with a history of trauma are at particular risk of distressing experiences occurring and to find out what solutions can be implemented to improve their health care experiences and reduce the risk of re-traumatisation.

Existing evidence shows that childhood trauma, including childhood sexual abuse, is very prevalent, and individuals receiving gynaecological care are at particular risk of re-traumatisation (Fanslow et al., 2007; Farley et al., 2002; Felitti et al., 1998; McGregor et al., 2013; McGregor et al., 2010; Modesitt et al., 2006; Sperlich et al., 2017). Furthermore, individuals with a history of trauma are more likely to have health issues, resulting in them being overrepresented in health care settings (Farley et al., 2002; Felitti et al., 1998; Hamberger et al., 2019). Finally, research shows that institutional settings such as hospitals are potentially triggering environments (Bryson et al., 2017; Bunting et al., 2019; Isobel & Edwards, 2017; Muskett, 2014; Raja et al., 2015, p. 216; Reeves, 2015). This review of the literature confirmed the researcher’s assumption that individuals with a history of trauma are at high risk of re-traumatisation in health care settings.

It was by reviewing the literature that the researcher discovered trauma-informed care (TIC), a practice model specifically designed to improve the care experience of individuals with a history of trauma. TIC highlights the importance of specific practice principles including safety, trustworthiness, choice, collaboration, and empowerment (Fallot & Harris, 2009). It also focuses on the provision of training and education to staff, so that they can understand the prevalence of trauma and recognise its symptoms and behaviours. Training enables staff to identify when an individual is being triggered and respond in ways that minimise the impacts of re-traumatisation. TIC also highlights the importance of screening for trauma so that individuals with a particular vulnerability to triggering can be identified. Finally, TIC focuses on consumer empowerment and highlights the importance of drawing on consumer expertise and preferences when providing care, as well as seeking the views and preferences of consumers when developing and implementing TIC systems (Fallot & Harris, 2009).

However, while TIC appeared promising there is still a gap in the evidence of its use and effectiveness within health care settings which is further discussed below.

1.4 Gap in the Literature

TIC practice highlights the importance of seeking the views and preferences of consumers when working in a trauma-informed way. It also emphasises the central role of consumer involvement in developing and implementing TIC systems. However, very few TIC studies have been conducted in hospital settings, other than in the field of psychiatric care (Isobel & Edwards, 2017; Muskett, 2014; Procter et al., 2017), and there is a gap in the research on consumer care experiences in these settings. Moreover, very few TIC studies have examined the health care experiences and preferences of gynaecology patients with a history of trauma, in hospital inpatient settings.

It was through the process of reviewing the literature and identifying gaps in the literature that the researcher formed the rationale for conducting this study. A more comprehensive examination of the reasons why gynaecology patients with a history of trauma are at high risk of having distressing experiences and a more detailed review of TIC and the argument supporting its introduction into hospital settings is outlined in chapter two.

1.5 Study Aim

This study aims to explore the health care experiences and preferences of the RWH gynaecology inpatients who have a history of trauma and will examine these experiences against trauma-informed principles of care. The study aims to find out what aspects of their care went well, what did not go well and what could be done differently to reduce the risk of re-traumatisation. This will expand and deepen our understanding of the needs of these patients and help identify ways that RWH can better meet these needs.

1.6 Significance of Research and Proposed Benefits

While this is an exploratory research study, it is intended to be used as a platform for improving the care experiences of gynaecology patients with a history of trauma and reducing distressing experiences from occurring. By learning about the health care experiences of this patient group, the study aims to identify what can be done to improve their care.

The research findings will be promoted across the hospital and used to continue to build on the evidence base of TIC. The research findings will also help fill the gap in research of exploring the views, preferences, and experiences of trauma-informed care of gynaecology patients in an inpatient hospital setting.

1.7 Research Questions and Hypothesis

The primary research question is: What are the health care experiences and preferences of gynaecology patients with a history of trauma?

The subsidiary questions are:

a. What factors, both negatively and positively, contribute to the health care experiences of gynaecology patients with a history of trauma?
b. What are the care perceptions and preferences of this patient group?
c. What aspects of their care went well, what did not go well and what could be done differently?
d. In what ways did their care align with trauma-informed care principles of safety, trustworthiness, choice, collaboration, and empowerment?
e. Were the patients screened for a history of trauma or distressing experiences?

The assumption underlining this study is that many patients have histories of trauma which increases their risk of having potentially traumatising health care experiences. As such health care practices need to be tailored so that they are more trauma-informed to reduce the risk of re-traumatisation. The basis of this assumption will be discussed further in the literature review.

1.8 Thesis Overview

Chapter One: Introduction

Chapter one outlined the study context, rationale, aim and research question.

Chapter Two: Literature Review

Chapter two will outline the key literature which informed the rationale for this study and examine the strengths and limitations of trauma-informed care as a practice framework designed to reduce the risk of re-traumatisation.

Chapter Three: Methodology

Chapter three will outline the study design, describing the methods used in the study and the reasons why these methods were chosen. It will then outline the recruitment strategy and data analysis method used, particularly reflexive thematic analysis, and the rationale for using this method. Finally, it will outline any ethical issues which were considered.

Chapter Four: Findings

Chapter four will describe the findings from the study and using thematic analysis, organise these findings into key themes, linking the findings back to the literature to see if they support, extend, or refute existing practice understandings and knowledge of TIC.

Chapter Five: Discussion

Chapter five will discuss how the findings contribute to existing research, highlighting findings which contribute to new knowledge. It will also discuss the ways in which the findings answer the research question. Finally, it will outline study implications and limitations and recommendations for the direction of future research.

Chapter Six: Conclusion

Finally, chapter six will summarise the study and key findings.

Chapter 2: Literature Review

This chapter outlines some of the main reasons why patients with a history of trauma are at high risk of re-traumatisation within health care settings. It then goes onto examine trauma-informed care (TIC), a framework aimed at reducing re-traumatisation, the principles of TIC, and TIC's particular focus on screening for trauma, staff training and education, and the empowerment and voice of the consumer. It then examines the literature on the effectiveness of TIC and identifies any gaps in the literature. Finally, it examines some of the different and at times opposing definitions of trauma and outlines the researcher's rationale for broadening the participant eligibility to include individuals' who self-identify as having history of trauma as well as individuals with more formal psychiatric diagnoses such as post-traumatic stress disorder (PTSD).

2.1 Why are Patients With a History of Trauma at Risk of Distress?

The literature shows that it is common for individuals with a history of traumatic or painful life events to have distressing incidents within hospitals and other health care settings (Elliott et al., 2005; Isobel & Edwards, 2017; Muskett, 2014; Reeves, 2015). This is for several reasons which are outlined below.

2.1.1 The Number of Individuals who Have Experienced Childhood Trauma is Very High

According to many studies, the prevalence of childhood abuse and trauma is actually very high (Fanslow et al., 2007; McGregor et al., 2013; Sperlich et al., 2017). For example, one study sample of over 214,000 individuals found that approximately 60% of the sample population had experienced at least one adverse childhood experience (ACE) such as physical, psychological, and sexual abuse, household family violence, mental illness, or substance abuse, and nearly a quarter of the sample had experienced three or more ACEs (Merrick et al., 2018). Other studies have found that one in four or five women or individuals assigned female at birth (AFAB) are survivors of childhood sexual abuse (Fanslow et al., 2007; Sperlich et al., 2017). As such, the likelihood of female or AFAB individuals having experienced childhood trauma is very high.

2.1.2 Individuals with a History of Trauma are Overrepresented in Healthcare Settings

Research also shows that individuals with a history of childhood trauma are more likely to have multiple health comorbidities, resulting in them being overrepresented within healthcare and hospital settings. According to Felitti et al.'s (1998) landmark ACE study, there is a strong correlation between trauma exposure and negative health outcomes, and individuals who have histories of childhood trauma are more likely to have chronic health or mental health issues, resulting in higher rates of hospitalisation. Moreover, other studies show that individuals with a history of childhood trauma have a higher number of hospitalisations and mental health visits (Hamberger et al., 2019, p. 432).

According to research, women who have experienced adult or childhood trauma are also overrepresented in many health conditions relating to female reproductive organs. For example, Modesitt et al. (2006), discovered that individuals who have experienced childhood trauma experience higher rates of gynaecological and breast cancer. Farley et al. (2002) found that individuals with a history of childhood sexual abuse (CSA) are at higher risk of developing cervical dysplasia. More specifically, individuals with a history of CSA are less likely to have pap smears which puts them at an increased risk of cervical cancer. Sperlich et al. (2017) report that ACEs are also linked to higher rates of pre-term birth, postnatal depression (PND) and teenage pregnancies. Moreover, Reeves (2015) showed that there is a high prevalence of trauma amongst individuals with Chronic Pelvic Pain (CPP), while Liebermann (2018), discovered that there is a high prevalence of trauma amongst individuals with endometriosis.

One study found that pregnancy care can be potentially triggering to those with a history of CSA (Sperlich et al., 2017). According to Seng et al. (2009), women with PTSD are more likely to be younger and access antenatal care later than other women and are also more likely to have socioeconomic risk factors associated with stress and PTSD (Seng et al., 2009).

2.1.3 The Hospital Setting is a Potentially Triggering Environment

According to some studies, the hospital setting is itself potentially triggering (Elliott et al., 2005; Reeves, 2015). This is in part due to the fast paced, high volume and time pressured nature of the hospital setting, where for clinicians, the challenge of juggling unwell patients, while providing individualised healthcare, is a fine balancing act. According to many studies, the physical environment of hospitals can be noisy, over stimulating, and clinical, and patients can often feel limited control over their own bodies and dependent on others for care (De Lima Andrade et al., 2021; Shattell et al., 2005; Ulrich et al., 2008; Williams et al., 2008). The literature emphasises the importance of clinicians providing clear and regular communication and reassurance to patients who are seeking to find control in a situation where they have little autonomy (Shattell et al., 2005; Williams et al., 2008).

Existing evidence also shows that it is not uncommon for individuals with a history of childhood trauma to experience a distressing, or “triggering” event during the provision of healthcare and that there are a multitude of potential triggering aspects of health care (Elliott et al., 2005; Hamberger et al., 2019, p. 426; Reeves, 2015).

2.1.4 Many Individuals who have a History of Trauma have had Negative Experiences within Institutionalised Settings

Past traumatic events experienced by individuals with a history of childhood trauma have often occurred within institutional and service settings. For instance, some individuals have had involuntary admissions into psychiatric hospitals (Azeem et al., 2011; Bryson et al., 2017) and others have grown up in out of home care settings such as group homes (Bailey et al., 2019; Bunting et al., 2019). Their experience of rules and authority may not be positive, and they may view the hospital setting with suspicion and mistrust (Reeves, 2015).

Furthermore, the hospital environment comes with its own hierarchy of authority and expertise. Patients with a history of childhood trauma and abuse may view individuals in positions of authority as “stand ins” for past abuses by people in power, a point highlighted in many studies (Elliott et al., 2005, p. 468; Knight, 2019; Reeves, 2015).

According to some research, giving over bodily control to another person in authority, combined with the fear of loss of control can increase the risk of re-traumatisation (Elliott et al., 2005; Raja et al., 2015; Reeves, 2015). Moreover, according to Reeves (2015) “the interpersonal dynamics of physical examinations – such as being told to relax or feeling trapped or restrained – can mimic the dynamics of abuse or violence and trigger memories” (p. 699).

Moreover, according to Pringle (1998), medicine has historically been a very male-dominated and hierarchical profession. Doctors have historically been viewed as “experts” whose authority over their patients is not questioned (p. 57). The feminist movement criticised gynaecology and obstetrics for using methods of surveillance and control over women’s bodies, through the overuse of medical interventions and technology and views this surveillance and control as a misuse of power over women and an aspect of patriarchy.

Despite the move in recent years to a more egalitarian and collaborative relationship between doctors and patients and the increase in numbers of women entering the medical profession, significant power differentials remain. Given that much childhood trauma is the result of the misuse of power, being treated by a male medical professional, who is in a position of authority, can still be triggering for some patients and the gulf between what medical professionals may think is best for the patient and what the patient wants, is still very wide (Pringle, 1998).

Finally, there is an expectation from patients that institutions such as hospitals are set up to care for people and protect them from harm. When harm does occur, expectations are violated, and trust is betrayed. This constitutes a form of “institutional betrayal” (Smith & Freyd, 2014, p.577). Moreover, historically, many marginalised groups including First Nations people, have experienced discrimination and maltreatment within institutions such as hospitals (Atkinson et al. 2010). This constitutes a form of “institutional betrayal”.

2.1.5 Gynaecological Conditions Occur within one of the Most Intimate Parts of the Body

Evidence suggests that for women with a history of childhood trauma, who are pregnant (Sobel et al., 2018) or have gynaecological conditions including cancer (Schnur et al., 2018), certain treatments or procedures have the potential to be traumatising or re-traumatising. Potentially traumatising practices include internal examinations, being asked to wear nothing more than a hospital gown, having a male practitioner in the examination room or having too many practitioners in the room (Reeves, 2015). Raja et al (2015) identified some of the potentially triggering aspects of medical care in her study:

> trauma survivors often report that lack of control in medical settings increases their anxiety. Many patients without trauma histories report mild to moderate levels of fear and discomfort particularly with needles and injections, whereas trauma survivors often report a wider variety of concerns, including having their bodies exposed, fear of powerlessness or being alone with an unknown provider, fear of having something inserted into their body, fear of not being able to breathe/swallow, fear of being touched, and fear of being unconscious. (p. 218)

It was due to an increased awareness of the prevalence of childhood trauma and its impact on health that TIC developed as a practice framework designed specifically as a way to work with individuals with a history of trauma, improve their care experience and reduce the problem of re-traumatisation. The next section examines TIC and its potential for being incorporated into health care settings and examines literature evaluating its effectiveness.

2.2 Trauma-Informed Care, a Solution to the Problem?

Trauma-informed care (TIC) has gained widespread recognition in recent years, particularly in the provision of health care services. TIC highlights the prevalence of trauma and recognises that individuals with a history of trauma often come into contact with institutions such as hospitals. It recognises the fact that re-traumatisation is more likely to occur within these institutions (Fallot & Harris, 2009), both directly, through intrusive care practices or the use of seclusion and restraints in psychiatric hospitals, or indirectly, through negative judgments and practices which might inadvertently trigger traumatic responses (Azeem et al., 2011; Isobel & Edwards, 2017; Muskett, 2014; Raja et al., 2015).

Since the inception of TIC, a plethora of different practice frameworks have been developed and implemented (Jennings, 2004). Many of these frameworks have been applied in different service settings such as homelessness (Hopper et al., 2010) and out of home care (Bailey et al., 2019), and their different strengths and weaknesses have been explored.

One notable TIC framework, because of its simplicity and easy applicability, is that of Fallot & Harris (2009). Fallot & Harris (2009) emphasise the importance of minimising the risk of re-traumatisation through adherence to certain principles. They highlight the importance of screening for trauma and training staff so that they aware of the prevalence of trauma and can better identify it and understand its impacts. They also recommend consultation at all levels and incorporating the views of staff and consumers into the design and delivery of TIC.

Fallot and Harris’ TIC framework (2009) has been adapted and evaluated within many different contexts (Elliott et al., 2005; Hanson & Lang, 2016; Hendricks et al., 2011; Jennings, 2004; K Hopper et al., 2010). It has also informed the development of many validated tools to measure staff perceptions and attitudes in relation to TIC (Baker et al., 2016; Hales et al., 2019). However, few tools measuring patient and consumer perceptions have been developed, though some work is currently being done in this space (Kusmaul et al., 2019).

It is for these reasons that Fallot and Harris (2009) was selected as a possible model of care that could be incorporated into the health care setting. The following section describes key aspects of Fallot & Harris TIC framework before examining literature which evaluates the effectiveness of TIC.

2.2.1 Fallot and Harris' Trauma-Informed Care Principles

Maximising Safety and Trustworthiness: This principle highlights the importance of individuals feeling both psychologically and physically safe within a service setting. To feel safe, a person needs to feel respected, listened to, and validated. Trustworthiness is enhanced by clinicians when they are clear about their role, consistent in how and what they communicate, ensure privacy and confidentiality, and set clear boundaries with the service user. Safety includes cultural safety, making the place feel welcoming to diversity and difference and free of judgmental, negative attitudes.

Maximising Consumer Choice and Control: This principle highlights the importance of ensuring the individual is given the option of making choices in their care, even if they are just small choices. This helps individuals feel more in control and reduces feelings of powerlessness.

Maximising Power Sharing and Collaboration: This principle emphasises the importance of ensuring individuals feel involved, as much as possible, in decision making. This helps increase the individual's sense of control. The individual is viewed as the expert in their own life, and the clinician draws on their knowledge and experience when working with them. The clinician is also discouraged from using "power over" the individual.

Empowerment: This principle focuses on giving the individual a voice in both their own care and the planning and implementation of services. It emphasises the importance of growth, quality of life and independence rather than just maintaining the status-quo.

Trauma Screening: This principle highlights the value of screening for abuse, in a sensitive, confidential, and supportive way and having options available for support referrals if the individual discloses abuse through the screening process.

Staff Training and Education: This principle highlights the importance of staff training, so that they can develop an understanding and awareness of the signs and symptoms of trauma. It also emphasises the importance of clinicians' reflecting on their own trauma history or vicarious trauma experiences to ensure these experiences do not negatively impact on the way that they respond or avoid responding to traumatised individuals.

The concept of empowerment and the voice of the consumer, the arguments for and against screening for trauma and the importance of staff training and education are discussed in more detail below (Fallot & Harris, 2009).

2.2.2 Empowerment and the Voice of the Consumer

Fallot and Harris' (2009) TIC framework highlights the importance of the voice of the consumer when working in a trauma-informed way and incorporating TIC into organisational systems; however, a frequent criticism cited in the evaluation of TIC systems is the lack of inclusion of the voices of consumers in the development, implementation, and evaluation of these systems (Bryson et al., 2017; Bunting et al., 2019; Purtle, 2020). Nevertheless, there are some qualitative and mixed method studies worth noting, which do examine the health care experiences and views of consumers who have histories of trauma. These are discussed below.

According to McGregor (2010), Raja et al. (2015) and Sobel (2018), in their studies of pregnant patients with histories of trauma, patients want health practitioners (HPs) to ask them about their trauma history in advance, explain clearly the reason and rationale for a particular course of treatment, check in with them regularly during treatment and tell them that it is okay to ask for their treatment to be stopped at any time (McGregor et al., 2010; Raja et al., 2015; Sobel et al., 2018).

O'Brien et al. (2007), conducted fourteen interviews and focus groups, to look at the experiences of women with a history of CSA accessing and using services and found that a lack of consistent standards and care models influenced their experience (O'Brien et al., 2007).

Price et al. (2006) interviewed twenty-six chronic pelvic pain patients about their experience of the gynaecology outpatient clinic and found that patients often felt dismissed and not taken seriously and felt their care was "depersonalised" (Price et al., 2006). The study found that female patients wanted to be given reassurance and clear explanations of their health condition. These aspects of health care were viewed as being just as important as being cured of the condition.

Purkey et al.'s (2018) study conducted in-depth interviews to explore the primary care experiences of twenty-six female patients with a history of childhood trauma. Purkey identified that continuity of care, whether or not the service was aware of their abuse history, environmental factors, care plan engagement and choice were most important (Purkey et al., 2018).

Reeves & Humphreys (2018) conducted semi-structured interviews to examine the health care experiences of fourteen female survivors of violence and found that developing trust and screening for trauma were most important (Reeves & Humphreys, 2018).

Ross et al. (2023) examined the health care experiences of forty-two patients with chronic pelvic pain and conducted focus groups using a semi-structured interview format with twenty-two patients both with and without a history of trauma. All patients described previous negative health care experiences, in particular feeling dismissed by clinicians, using repetitive testing, even when this testing had been done previously and having psychological reasons attributed to their symptoms. Ross et al. (2023) defined distressing health care experiences as a form of "institutional betrayal" (p. 482) and explored some of the ways organisations risk retraumatising individuals with a history of trauma, for instance, by minimising their health concerns or not believing them (p.482).

According to the patients interviewed by Ross et al. (2023), the care (either negative or positive) provided by individual clinicians was crucial to patients' health care experience, how well they coped with their condition and whether they decided to access further care in the future. Patients highlighted the importance of environmental factors such as how inviting or comfortable the outpatients setting was and how friendly staff were; they also emphasised patient choice and control, the importance of getting advance consent for trainees to be in the room, having reasons for treatments or investigations explained to them, and the offer of a female chaperone to examinations as important. Some patients saw the gender of the clinician as important; other patients recommended trauma screening, the offer of a female chaperone when having examinations conducted or the offer of an advocate or social worker to support them to navigate the health care system as important (Ross et al., 2023).

Schnur et al. (2018) used open-ended questions in their quantitative study to look at the cancer treatment experiences of childhood sexual assault survivors. They identified procedure-related triggers, such as distress caused by the way an examination reminded individuals of past traumatic events, and provider-related triggers, such as distress caused by for instance, unfamiliarity with or the gender of the HP. Schroll et al. (2013) examined abuses in health care experienced by survivors of childhood trauma and concluded that "dehumanisation" and "bodily remembrance" were common themes (p.1).

While most of these studies were small and did not specifically examine the health care experiences of gynaecology inpatients, they were notable in that they did examine some aspects of the patient health care experience. They also identified ways in which care experiences both align with and do not align with the principles of TIC and ways to improve care so that it is less re-traumatising.

2.2.3 Screening for Trauma

According to some studies, (McGregor et al., 2013; and Reeves, 2015) it is difficult for clinicians to identify those women at most risk of distress or potential re-traumatisation, because screening for trauma, is not usually standard practice. This is despite studies showing the prevalence of physical, sexual, and psychological childhood abuse.

Studies of health practitioners’ (HPs) screening practices show that they are reluctant to ask their patients if they have a history of CSA due to lack of time, a belief that it is not part of their job and because they do not feel adequately equipped to respond appropriately if the person discloses a trauma history (Hurst et al., 2003; McGregor et al., 2013). According to McGregor et al. (2013), HPs will only modify their practice if they know that the patient has a history of CSA.

This is despite evidence which shows that most patients only experience short term discomfort when asked to share sensitive information with HPs. According to many studies, as long as HPs are trained to respond to disclosures, the reason for asking sensitive questions is made clear, the trauma screening is voluntary and HPs offer to link them into appropriate support services if needed, patients usually find sharing sensitive information a positive experience (McGregor et al., 2010; Read et al., 2007; Snyder, 2016).

2.2.4 Staff Training and Education

Trauma-informed care aims to educate staff about some of the symptoms of childhood trauma, such as dysregulation, self-harm, and substance misuse. Staff are encouraged to re-frame these symptoms as mechanisms which individuals develop to cope with childhood adversity and traumatic events (Machtinger et al., 2015). They are also shown some of the ways that trauma impacts on the way the individual views the world, often with mistrust (Elliott et al., 2005).

According to Jennings (2004), educating staff in TIC helps them to create context and understanding for the behaviours of these individuals and reduce judgmental and negative attitudes towards them. It also helps staff identify potential “triggers” for re-traumatisation so that they can reduce the likelihood of triggering situations occurring.

Finally, TIC emphasises the fact that many staff members have also experienced traumatic events in their lives, and that working with individuals who have experienced traumatic histories can often result in them experiencing vicarious trauma. Raja et al. (2015) emphasise the importance of staff being aware of their own triggers and reactions to traumatised individuals. Staff who are not aware of their reactions, may inadvertently avoid asking trauma-screening questions, or react negatively towards them (Raja et al., 2015).

2.3 How Effective is Trauma-Informed Care?

There is some evidence of the effectiveness of TIC in psychiatric care (Azeem et al., 2011; Bryson et al., 2017; Muskett, 2014) particularly in the areas of reducing the use of seclusion and restraints (Azeem et al., 2011). Bryson et al. (2017) conducted a systematic review examining staff satisfaction, patient, and staff injuries as well as reductions in use of seclusion and restraints. Evidence showed an increase in staff satisfaction and decline in use of seclusion and restraints. The evidence also highlighted that leadership prioritising TIC, staff training and supervision, listening to patients and families’ needs were central to success in reducing the use of seclusion and restraints (Bryson et al., 2017).

Empirical research evaluating the effectiveness of TIC is even more limited in public hospital settings. Reeves (2015) conducted a systematic review of twenty-six studies and concluded that although TIC was promising, only a few studies have been conducted to evaluate its effectiveness and these studies have several weaknesses. Furthermore, Purtle (2020) conducted a systematic review of a range of difference organisations, including hospitals and mental health services, which evaluated the effects of organizational interventions which included a “trauma-informed” staff training component” (Purtle, 2020, p. 726). He concluded that TIC improved staff knowledge, attitudes, and behaviours related to trauma-informed practice post training; however, he also pointed out the limitations to the methodologies of these studies such as the post training follow-up time frames were very short, and the survey responses were self-reported (Purtle, 2020, p.738).

There are moves towards evaluating the effectiveness of TIC in the field of homelessness, though this is still in its early days (Hopper et al., 2010). There is also some evidence which shows TIC’s effectiveness in children’s out of home care (Bailey et al., 2019; Bunting et al., 2019); however, many of these studies have also been critiqued for having weak study designs, small sample sizes and limited consumer engagement (Bunting et al., 2019, p.17), or evidence has been seen as weak and with a high risk of bias (Bailey et al., 2019, p.20).

Trauma-Informed Versus Trauma-Focused Services: It is important to emphasise that *trauma-informed services* are different to *trauma-focused services*, which are often delivered within organisations which provide trauma-informed services. Trauma focused services are designed to work *directly* with the impacts of trauma, whereas TIC is more of *a practice approach* for working with people and is embedded within organisational policies, training, best practice guidelines and consumer feedback processes (Hopper et al., 2010).

2.4 Defining Trauma

There are competing definitions in the literature of the term “trauma” and differing views about what makes an event “traumatic”. However, because this study focuses on the health care experiences of individuals with a history of trauma, decisions about eligibility to participate in the study had to be made. As such, it was necessary to examine the literature on trauma, so that decisions could be made about who to include and exclude in the study. The next section appraises this literature and some of the key debates about what constitutes as "trauma" or "traumatic" and the rationale for electing upon a broader definition of trauma when deciding on who was eligible to participate in the study.

Mersky et al. (2019) define traumatic events as those which cause psychological distress or harm, and "overwhelm" the individual's internal resources (Mersky et al., 2019, p. 646). These authors acknowledge the challenges of deciding what is or is not "traumatic" and draw attention to the debate in the literature as to whether events which have fewer lasting effects can be defined as traumatic. They believe that many conditions do not meet the criteria for a Post Traumatic Stress Disorder (PTSD) diagnosis but may still be traumatic and cause significant distress. They use the term "potentially traumatic event" (PTE) as a solution to this problem. They define PTEs as "threatening or highly stressful events or conditions that are capable of overwhelming an individual's capacity to adapt" (Mersky et al., 2019, p. 646). Examples of PTEs include family violence, physical and sexual abuse, medical and vicarious trauma.

The term "adverse childhood experience" (ACE) was used by Felitti et al., (1998) in their landmark study. Felitti et al., (1998) identified ten different categories of abuse, neglect, and household dysfunction. They argued that a higher number of ACEs correlates with a higher number of chronic health issues (Felitti et al., 1998; Larkin et al., 2014).

However, the term “trauma” comes with a range of complexity and difficulties and is defined differently in different contexts. Some authors have pointed out the difficulty of defining trauma without acknowledging the subjective nature of an individual’s experience (Mersky et al. 2019). They point out that the emotional reaction to a traumatic event and the way the event is perceived might vary from one person to another, as well as across communities and cultures (Mersky et al. 2019). Moreover, according to other authors, the term “trauma” can refer to the event *or* the impact that the event has on the individual (Atkinson et al., 2010, p. 135).

Herman (2015) asserts that it is the extreme powerlessness and helplessness experienced by the individual resulting in the physiological responses of hyperarousal, intrusion and constriction that makes events “traumatic” (p.34). Moreover, Rothschild (2000) asserts that traumatic events can result in lasting psychological and physiological effects which impact on the individual’s psychological development and their body and limbic system. The limbic system releases hormones in response to a perceived threat. This tells the body to prepare for “defensive action”, and mobilises the body to fight, flight or freeze (Rothschild, 2000, p.7). Hyperarousal includes rapid breathing, heart palpitations, hypervigilance, jumpiness, loss of appetite, sleep disturbance and difficulties concentrating (Rothschild, 2000, p. 7).

According to Procter et al. (2017), when stressed or experiencing “a heightened state of emotional stimulation”, the body stress response system is at risk of becoming overstimulated (p. 5). Moreover, if the limbic system continues to be chronically aroused even once the threat has passed, the individual is at risk of developing PTSD. According to Rothschild (2000), symptoms of PTSD include re-experiencing the event in sensory forms such as flashbacks, avoidance behaviours to avoid reminders of the trauma and chronic hyperarousal of the autonomic nervous system (p.47).

Some authors argue that traumatic events can also impact on the individual’s coping styles and sense of self; furthermore, people who have experienced trauma, might form a view of the world as dangerous and untrustworthy, due to their negative experiences (Kezelman & Stavropoulos, 2012; Van der Kolk, 2017).

However, many authors believe that some definitions of trauma have been privileged over others and view the definition of trauma as political (Brown, 2004; Burstow, 2003; Davis, 1999). For instance, conditions resulting from traumatic events, such as PTSD, have been rigorously debated by many authors who assert that the diagnostic criteria for PTSD are underpinned by Western, privileged and patriarchal assumptions; while other forms of trauma, such as intergenerational and community trauma, and the intersecting forms of trauma experienced by some marginalised groups, are not given the same attention (Brown, 2004; Burstow, 2003; Davis, 1999; Elliott et al., 2005; Mersky et al., 2019).

Some authors also contend that repeated traumatic events occurring during childhood can result in the development of conditions such as developmental trauma or complex PTSD (Cloitre et al., 2009; Courtois & Ford, 2009; Van der Kolk, 2017). However, complex PTSD presents differently to PTSD and has only recently been recognised within the WHO International Classifications of Diseases (Karatzias et al., 2019). Despite years of campaigning, complex PTSD has yet to be recognised as a distinct condition by the American Psychiatry Association’s (APA) Diagnostic and Statistical Manual of Mental Disorders (DSM-5) (Cloitre et al., 2009). Moreover, many authors highlight that while not all distressing events have the same significant impact, it is the cumulative impact of multiple traumatic events, either small or large, over time, which causes the most harm (Stone et al., 2023).

The contentious nature of trauma is also highlighted by many feminist authors, such as Brown (2004) and Burstow (2003) who apply a critical feminist lens in their analysis of trauma and trauma theory. Brown (2004) views certain forms of trauma as the *"*intended consequences of institutionalised forms of discrimination such as sexism, racism, classicism*"* (Brown, 2004, p. 465); while Burstow (2003) believes that trauma theory has been hijacked by the field of psychiatry, resulting in trauma being depoliticised. As such, the conditions of inequality and disadvantage, which put some marginalised or oppressed groups at higher risk than others of trauma exposure, are ignored, and responsibility is placed upon the individual rather than society. According to Burstow (2003), "PTSD is a grab bag of contextless symptoms, divorced from the complexities of people's lives and the social structures that give rise to them. As such, the diagnosis individualizes social problems and pathologizes traumatized people" (p.1296).

Many authors highlight the increased risk to trauma exposure of some particularly disadvantaged and marginalised groups, such as refugees and First Nations people (Atkinson et al., 2010, p. 262; Tummala-Narra, 2007, p. 321). They argue that those experiencing intersecting forms of trauma have not been adequately considered in the development of definitions of trauma (Burstow, 2003; Tummala-Narra, 2007). There is compelling evidence which shows that intergenerational, community and historical trauma have been experienced at much higher rates within certain groups such as First Nations people (Atkinson et al., 2010). As such, some authors, such as Mersky et al. (2019), believe trauma should be viewed as an issue of economic and social justice: “Across the globe, the burden of certain PTEs [potentially traumatic events] such as child maltreatment, interpersonal violence, and natural disasters are borne disproportionately by economically disadvantaged and otherwise vulnerable populations” (p.647).

In the case of First Nations people, because much intergenerational trauma is the result of past government legislation and institutional racism, many institutions are viewed with mistrust. It is widely reported that the removal of First Nations babies during the stolen generation often occurred within hospital settings, so hospitals themselves are often viewed as culturally unsafe places for First Nations people (O’Donnell et al., 2019).

Authors such as Brown (2004), Burstow (2003) and Davis (1998) warn against looking to the field of psychiatry for answers when supporting people suffering the effects of childhood trauma. Burstow (2003) argues that relying on psychiatric diagnoses such as PTSD to understand trauma and its impact, can disempower people and subject them to further traumatisation:

> we take away people’s power to name their experiences and subject them to a naming controlled by a powerful international institution at arm’s length. Moreover, we increase the possibility of the person some day being subjected to more substantial psychiatric interference, for diagnoses are an entry point to more intrusive measures. The more severe the diagnosis, the more severe the treatment it can legitimate (p. 1300).

It is for the reasons outlined above that a decision was made to expand the eligibility criteria of the study to include both diagnosed and self-identified forms of trauma and to favour the individual’s perception of trauma or traumatic events over the use of formal diagnostic tools. Detailed examples of painful or traumatic life events can be found in chapter 3.

Chapter Summary

This chapter set out to explain some of the reasons why gynaecology patients with a history of trauma are at such high risk of re-traumatisation within health care settings. It appraised TIC, a framework aimed at reducing the risk of re-traumatisation, and explored the evidence of TIC's effectiveness and the gaps in the literature, particularly around the voice and experience of patients. Finally, different competing definitions of trauma were discussed, and the rationale for electing to maintain a broad definition of what constitutes as "trauma" or "traumatic" when recruiting participants to the study was analysed.

Chapter 3: Methodology

This chapter will outline the methodology used for this study. To start with, the research design and rationale for conducting a qualitative study using semi-structured interviews will be examined. Secondly, the study population, sample method, eligibility criteria and ethical issues will be discussed. Thirdly, the recruitment strategy and some of the recruitment challenges will be outlined. Finally, the rationale for using Braun and Clarke's reflexive thematic analysis (RTA) to analyse the data will be explored (Braun & Clarke, 2006, 2019).

3.1 Research Design

This study used a qualitative research study design. According to Liamputtong (2016), qualitative methods are better than quantitative methods for answering complex questions when working with vulnerable populations (Liamputtong, 2016). Qualitative methods focus on behaviour, perceptions and experiences of individuals and the factors which influence these (Liamputtong, 2016). They also situate the researcher within the research, acknowledging their role in interpreting and finding meaning while also emphasising their own biases and assumptions and not claiming to be objective (Braun & Clarke, 2019; Creswell & Poth, 2016). Given that the study aims to explore patient health care experiences, a qualitative research design was viewed as being better placed to answer the research question.

This study took a constructivist view of reality. The constructivist paradigm views reality as being socially constructed and shaped by multiple factors such as gender, race, class, and life experience. It holds the view that there are multiple truths, and that both research participant and researcher's interpretations of reality are subjective and shaped by their social positioning (Denscombe, 2010; Liamputtong, 2016). This is opposed to a positivist view, that there is one objective, measurable reality, and the researcher can take a neutral, objective standpoint when conducting research. This approach emphasises the role of culture and how individuals mediate meanings and interpretations through shared cultural meanings. It views research participants as active participants in the construction of knowledge within the research process and emphasises the individual's perceptions and meanings of their subjective experience (Liamputtong, 2016).

3.2 Population, Sampling Method, Inclusion, and Exclusion Criteria

The study was conducted at RWH, and the study population were gynaecology patients of RWH who self-identify as having had challenging or painful (traumatic) life events and who were admitted to hospital between February and December 2022, for either emergency or planned treatment of gynaecology conditions.

The sampling strategy used was purposive, in that participants were selected based on their capacity to answer the research question (Robinson, 2014). Participants share key demographic characteristics in that they are gynaecology patients who had inpatient stays at RWH and self-identified as having a history of trauma.

Some authors argue that decisions about sample size should be made for theoretical reasons and theoretic saturation point, the point at which no new themes emerge, should dictate the size of a sample (Lofland & Lofland, 1971). However, like Braun and Clarke (2019), this researcher argues that the concept of "saturation" is a very positive one, not in line with the constructivist approach to qualitative research. The concept of "saturation" disregards the role that the researcher has in making decisions about "saturation", and the subjective and interpretivist nature of data analysis. Moreover, because this was an exploratory study and part of a Research Masters, and there were time and resource constraints, decisions about sample size were primarily made for practical reasons.

The goal was to recruit between 15 to 20 participants, which is considered an adequate size for a qualitative study, because the population frame is relatively homogenous and the research question relatively narrow (Thomson, 2010). Rigorous procedures were followed in the recruitment, sampling, coding, and data analysis process (Tong et al., 2007), and the researcher used a reflexive approach to coding and analysis (Berger, 2015; Braun & Clarke, 2019). As such, it can be argued that the findings are “dependable”, “confirmable”, “transferable” and “credible” (Liamputtong, 2016, p.17).

Exclusion and inclusion criteria were set for ethical reasons and to ensure the sample selected was precise (Robinson, 2014). Gynaecology patients admitted during the recruitment period, who self-identify as having a history of trauma, are over 18 years of age and have capacity to consent to participate were eligible to participate in the study. Due to the cost of using interpreters, only participants who have good spoken English were included. In order to focus on a particular type of patient experience and avoid the risk of having too diverse a population, making the findings less transferable to other contexts, only gynaecology patients were included in the sample, and patients who were pregnant or had a cancer diagnosis were excluded.

The eligibility criteria were expanded to include both diagnosed and self-identified forms of trauma and histories of adult and/or childhood trauma. Because the terms “trauma” or “abuse” are unclear, open to misinterpretation and might cause distress, more inclusive language was chosen in the recruitment of participants and the terms “challenging”, “distressing” or “painful” life events were used instead (Ferentz, 2015; Read et al., 2007).

For the purposes of this study, traumatic events include a history of childhood abuse such as physical, psychological, and sexual abuse and neglect; sexual assault; experience or witnessing family violence; experiencing or witnessing violent crime or natural disaster or war. However, this list is not exhaustive, and the person's perception of what constitutes as "challenging", "distressing" or "painful" was most important. Appendix 1 outlines the eligibility criteria.

3.3 Recruitment and Data Collection

The recruitment and data collection processes were adapted due to changing COVID19 pandemic restrictions. The Australian state of Victoria, of which Melbourne is the capital, had some of the most stringent restrictions on the movement of people, and face-to-face recruitment of research participants was not allowed in early 2022. The initial plan was to strategically place promotional posters with QR codes on them, in the bathrooms on the ward, as these are private and confidential spaces. The use of QR codes was selected because individuals were already familiar with using QR codes, due to the pandemic. This recruitment strategy was also selected to reduce the chance of individuals feeling pressured to participate and because of the initial restrictions on face-to-face recruitment.

However, due to the increased risk of COVID19 exposure in February 2022, (the omicron mutation), this strategy was changed, for infection control reasons. For the first month of the study, paper copies of the posters were placed on the bedside table of the ward beds instead, however, this strategy relied heavily on ancillary staff to replace posters after each patient discharge and was reliant on staff remembering to do this.

As such, by the end of the first month of recruitment, a request to put posters on the walls of the ward rooms was granted, though these posters were not as easy to view as posters placed in bathrooms would have been.

Nevertheless, recruitment remained slow, so an amendment was submitted to the Ethics Committee in May 2022, extending the recruitment period from a six to eleven-month period, and enabling the researcher and other members of the social work team to give promotional materials to potential research participants on their day of discharge from hospital. By this point infection control restrictions had eased slightly so face-to-face recruitment was allowed. Moreover, the flyer was sent out to the Epworth Freemasons Endometriosis Support Group inviting any members of the group who had been in hospital during the study period, and who met the other eligibility criteria to participate in the study.

Interviews were conducted either face-to-face or via the web-based online platform Web Ex. If individuals were unable to participate in face-to-face or web-based interviews, they were offered the option of doing the interview via telephone.

Using a video conferencing platform such as Web Ex has many benefits. RWH is a tertiary hospital and many patients come from regional areas. Offering the option of using Web-Ex meant that the study reached individuals who might not normally be able to participate for geographic reasons. Studies show that many research participants feel more at ease and more comfortable to talk freely when using technologies such as Web Ex (Archibald et al., 2019; Gray et al., 2020; Salmons, 2015; Torrentira, 2020). This is particularly important given the sensitive nature of the topic being studied. Using Web-Ex also removes other barriers to research participation, such as travel time and parking costs.

Data were recorded using an audio device and then transcribed. Transcribed data were checked for errors and stored confidentially at the Social Work department at RWH.

All data were de-identified and will be destroyed and deleted five years after final publication is completed.

To reduce the risk of patients feeling pressured to participate, promotional materials and verbal information were provided, but direct recruitment of patients was not allowed. Potential participants still had to express interest via the QR code, email, or telephone contact.

3.3.1 Data Collection Tool

Semi-structured interviews were conducted to collect data. They were selected because their informal, conversational nature can help the researcher to build rapport with participants, put them at ease and reduce the power differentials between both parties (Liamputtong, 2016). Semi-structured interviews only involve participant and researcher, which can help increase the sense of safety and confidentiality for participants who are being asked to discuss a sensitive topic. Using open-ended questions helped the researcher explore patient experience in depth. It also helped facilitate the inclusion of participants who are often hard to reach, marginalised or excluded from research.

Most of the interviews were conducted by the researcher; however, two of the interviews were conducted by the co-researcher, because these participants were known to the researcher from having been supported in their capacity as a social worker. Both researcher and co-researcher are qualified social workers, experienced in discussing sensitive topics with vulnerable individuals. Social workers practice principles closely align with those of trauma-informed care in that they emphasise choice, collaboration, safety, and empowerment (Levenson, 2017), making them well placed to conduct these interviews in ways that minimise the risk of causing distress and manage any potential adverse issues should they arise. According to Campbell et al. (2019) this is a trauma-informed approach to conducting research (Campbell et al., 2019).

Although there are multiple pre-existing tools to screen for and identify a history of trauma (Bernstein et al., 1998; Carlson et al., 2011), these validated tools were ruled out for the following reasons:

- The aforementioned contentious and politicised nature of the term “trauma”, PTSD or other forms of diagnosis, and the fact that some definitions of trauma have been privileged over others (Burstow, 2003).
- The intrusive nature of these lengthy tools.
- The focus of the study is on the hospital experience of these patients, ***not*** on their past trauma.
- The study was exploratory.

3.3.2 Interview Questions

Interview questions were designed in line with Fallot and Harris (2009) trauma-informed principles of safety, trust, choice, collaboration, empowerment, and trauma-screening. Patient experience was examined in relation to these care principles. A copy of the Interview Schedule is included - see Appendix 3. In line with the trauma-informed care principles of collaboration, choice and empowerment, participants were asked if they wanted a copy of their transcript (to ensure accuracy and for their own keeping).

3.4 Data Analysis

Data were analysed using reflexive thematic analysis (RTA), a form of thematic analysis set out by Braun and Clarke (2019). RTA was selected because it focuses on making sense of individuals’ lived experiences and is easy to learn and apply. Braun and

Clarke (2006, 2019) argue that their interpretation of thematic analysis can be used for either constructivist or realist approaches to data analysis, which makes it very flexible (Braun & Clarke, 2006, 2019; Lainson et al., 2019).

RTA emphasises the importance of the researcher being "reflexive" and able to critically reflect on their position of power, assumptions and biases when interpreting information (Berger, 2015; Braun & Clarke, 2019). RTA makes the researcher role visible and power explicit within the data analysis process. This was important, given the potential disadvantaged and marginalised nature of the group under study. According to RTA, the researcher is encouraged to take responsibility for their role in interpreting the data and acknowledge the role of power within this process. RTA views knowledge as "co-produced" between researcher and participant. To help level the power between researcher and participant, the interview was semi-structured, and participant led. Data analysis was theoretically driven, in that it was influenced by the researcher's knowledge of TIC literature.

Themes needed to be clear and distinct, and either capture something important in relation to the overall research question or be repeated throughout the data extract (interview) or across the whole data set, to avoid "anecdotalism" (Braun & Clarke, 2006, p. 95). Themes were developed by the researcher moving back and forth between individual data extracts and by examining the data set as a whole (Braun & Clarke, 2006, p.95). This formed the data analysis.

According to Braun and Clarke (2006, 2019), themes can be semantic (descriptive, surface level) or latent (interpretive level, meaning is constructed and reproduced within the social context, structural conditions. One of the benefits of using RTA is its flexibility, which allows it to be used in combination with other data analysis techniques or processes.

As such, it was used in combination with grounded theory coding techniques (Charmaz, 2006).

For the purposes of this study, something was only considered a theme if it captured "something important in relation to the research question" and if it was prevalent in the data set (Braun & Clarke, 2006, p. 82). A theme was viewed as dominant or significant if it was prevalent in half of the interviews. For instance, if participants continued to return to the same theme, or if the theme appeared to have particular value or meaning to them, this was considered significant. Also, subthemes were viewed as important if they were present in at least a third of the interviews but were significant in these interviews. Some noteworthy minor themes were discussed when they were only present in a few interviews but were significant in those interviews. The term "data extract" is one used by (Braun & Clarke, 2006, p. 79); however, at times, the terms "interview" or "transcript" are used instead of "data extract" depending on which term is most appropriate to the context.

When discussing the presence of themes in the interviews:

- "a few" means up to a third of all interviews.
- "many" means up to two thirds of all interviews.
- "most" means more than two thirds of all interviews.

The data analysis process is outlined in Appendix 4. This process illustrates the decisions which were made at particular points during the analysis and the reasons why these decisions were made. To illustrate how themes were developed, an extract of the analysed data is included in Appendix 5.

Charmaz (2006), a grounded theorist, believes that both interviewer and participant come to the interview with their own agendas, and grounded coding techniques help the research explore the interview from the participant's perspective. She asserts that grounded coding techniques study processes and actions, which help reduce the risk of the researcher being restrained by their own assumptions and preconceptions (Charmaz, 2006, p. 86).

The grounded techniques of line-by-line coding, “gerunds” and “in vivo” codes were used to analyse the data. Line-by-line coding is a technique which helps researchers avoid solely selecting those findings which back their assumptions and ensures the research does not miss anything important. “Gerunds” are types of code that use action verbs and help the researcher code for processes and actions. Finally, “in vivo” codes are codes which capture the terminology and language used by the research participants themselves. In vivo codes help encapsulate the world view or values important to the participant and are often specific to the social context and subculture of whom the participants are part (Charmaz, 2006, p. 50).

According to Charmaz (2006), using line-by-line coding and gerunds help researchers avoid making “conceptual leaps” and reduces the risk of “anecdotalism” (p.48). Gerunds also “crystalise the participants experience” and help the researcher make “implicit processes explicit” (p.50).

Braun and Clarke (2006, 2019) argue that if the researcher adopts a consistent approach when analysing data, is transparent about any underlying assumptions and theoretical approaches underpinning their analysis, and follows the loose guidelines they propose, while remaining flexible, then RTA can be viewed as a method in its own right. The benefit of RTA is its flexibility in that it can be used alongside other data analysis methods such as grounded theory coding techniques. RTA highlights the importance of transparency in the coding process and draws attention to the researcher’s role within the analysis process; while grounded theory helps ensure that the researcher remains open to new discoveries and reduces the risk of making assumptions when analysing data (Braun & Clarke, 2019; Charmaz, 2006).

3.4.1 Researcher Qualifications

I am a white, middle-class woman, who has worked for ten years in hospitals, and nearly six years in my current role supporting patients with gynaecological issues including cancer. I have an undergraduate honours degree in Sociology and a qualifying Master's Degree in Social Work obtained in 2012.

As a social worker, I view advocacy and social action as important. I view myself as a feminist and am passionate about equality of health access, particularly for women and AFAB individuals who have experienced intersecting forms of disadvantage within health settings. I am particularly interested in the hierarchical nature of hospitals and doctor-patient relationships, and how systems working in silos can influence the health care experience of marginalised and disadvantaged patients.

I came to the research interviews with an awareness that my position as social worker might affect the power dynamic within the interview setting. I tried to reduce this power differential through reinforcing the rights of the interviewee and by being transparent about my agenda for conducting the research study. I was aware, when analysing the data, of the risk of cherry picking those results which support my unconscious bias and beliefs relating to inequality in health and health access to women or AFAB people, which was why it was important for me to draw on the data analysis processes outlined by both Braun and Clarke (2019) and Charmaz (2006).

Authors such as Charmaz (2006) and Braun and Clarke (2006, 2019), support the use of journals and memo writing to help ensure rigour, thoroughness, and consistency in the data analysis process. I used a journal and wrote memos to document my reasons for making certain decisions and keep track of any changes to my data analysis process. I also used academic supervision to discuss my ideas and thinking. Supervision helped me develop the ability to articulate my reasoning so that I could defend any data analysis decisions that I made. It also provided scrutiny and feedback, which helped me ensure my decision-making and data analysis process were consistent and thorough.

3.5 Ethical Issues and How They Were Addressed

A Participant Information and Consent Form (PICF) was developed, to ensure participants were aware of what they are agreeing to do, and their rights to withdraw from the research at any time (see appendix 2). Participants had to be over 18, be able to read, and/or understand what they are agreeing to. To ensure individuals understand what they are agreeing to, the PICF was written in plain English.

A distress protocol was included on the Interview Schedule (see appendix 3), providing clear guidelines about how to manage potential distress during any stage of the research period. Any participant who became distressed was given the option of stopping the interview and receiving follow-up care. The Protocol stated that if a participant disclosed information that posed a threat to their safety or the safety of others, their confidentiality would be waived, and the appropriate authorities notified. Participants were informed of this in the PICF and reminded at the start of the interview. The distress protocol was developed in line with Draucker et al. (2009).

As mentioned earlier, both researcher and co-researcher are qualified and experienced social workers with skills to identify and respond to distress. They are trained to work reflexively and be aware of their own power. They are also trained at building rapport, while maintaining appropriate boundaries, which are ethical components critical to working with a vulnerable population (Hewitt, 2007). During the interview, the researcher was responsible for watching for signs of distress, regularly checking in with the participant and offering frequent breaks. However, there were very minimal signs of distress when conducting the interviews and only two participants took up the offer of the researcher or another social worker checking in on them a few days after the interview.

To avoid any conflict of interest, research participants could only be interviewed by someone who was not involved in their care. Potential participants were given promotional materials on their day of discharge but could only express interest through use of the QR code, emailing or phoning the research team. This was to reduce the risk of individuals feeling pressured to participate. The research was submitted to and approved by the Royal Women's Hospital Ethics Committee in December 2022.

A final ethical issue to make note of was that screening questions to identify history of childhood trauma were used to ensure individuals expressing interest in the study were eligible to participate (see Appendix 1). The eligibility screen was accessible by scanning the QR code. Alternatively, the researcher could conduct the eligibility screen via telephone. The eligibility screen was a set of questions asking individuals if they had ever experienced distressing or painful life events. Examples of distressing life events were listed on the screen, but it was made clear that this list was not exhaustive. Individuals who did not tick yes to this question, were not eligible to participate in the study.

Evidence suggests that although individuals feel discomfort when disclosing a history of abuse; if they understand the reasons for being asked questions, and are offered support if they feel distress, then this discomfort is minimal (Hamberger et al., 2019; Reeves, 2015). Furthermore, the benefits of screening, in highlighting the prevalence of abuse has been discussed at length, particularly in the Adults Surviving Child Abuse Guidelines developed in 2012 (now known as Blue Knot Foundation) (Kezelman & Stavropoulos, 2012). The eligibility screen clearly outlined the rationale for asking the questions; this helped reduce the risk of causing distress.

Chapter Summary

This chapter set out the qualitative research design used in this study and the reasons for selecting this design. The study population and the recruitment strategy were also set out, as well as some of the challenges and opportunities raised by the COVID19 pandemic. The data analysis process and the reasons why Braun and Clarke's RTA and grounded theory techniques were used is examined (Braun & Clarke, 2019; Charmaz, 2006). Finally, ethical issues that needed to be considered were outlined.

Chapter 4: Findings

In this chapter, the participant characteristics are outlined, such as their age, type of gynaecological condition being treated, reason for hospital admission and length of stay, see Table 1. Then five key themes and sub themes identified by the researcher in the data are outlined, and quotes from the interviews are used to illustrate the meaning of these themes. Finally, how each individual theme and subtheme relates to TIC and compares against existing TIC literature is explored, to see if the themes identified in the data support, refute, or extend our understanding of TIC practice.

4.1 Participant Characteristics

Table 1

Overview of Participants

Number of Participants Interviewed	• 15
Study Period	• February to December 2022
Interview Period	• March 2022 to June 2023.
Gender Identity	• Participants were not specifically asked about gender identity, however 2 volunteered their identity as male.
Age	• 3 were under 25 years old. • 6 were between 26 and 35. • 3 were between 36 and 45. • 2 were between 46 and 65. • 1 was over 65
Relationship Status	• 6 were single. • 5 were in de facto relationships. • 3 were married. • 1 was a widow.
Gynaecological conditions being treated	• 5 had endometriosis. • 2 had endometriosis and adenomyosis. • 1 had endometriosis and vaginal pain.

	• 1 had endometriosis, pelvic pain, and gender dysphoria. • 1 had endometrial hypoplasia. • 1 had severe pelvic pain. • 1 had a twisted fallopian tube and pelvic prolapse. • 1 had a gynaecological wound that was not healing. • 1 had a ruptured cyst.
Admission Type	• 6 had planned admissions. • 6 had emergency admissions. • 3 had both a planned and an emergency admission.
Interview Length	• Interviews were between 33 minutes to 1 hour and 22 minutes long.
Interview Mode	• 12 were conducted via Web Ex. • 2 were conducted via telephone. • 1 was conducted face-to-face.
Expressions of Interest	• 3 expressed their interest via email or telephone. • 12 expressed their interest via promotional posters and flyers.
Participants who Expressed Interest But Were Not Eligible for the Study	• 3 potential participants expressed interest in the study via email or telephone. • 44 potential participants expressed interest via the QR code located on promotional posters and flyers. • Of the 44 participants who expressed interest via QR codes, 14 were eligible to participate and the remaining 30 were not eligible for the following reasons: • 3 had a cancer or suspected cancer diagnosis. • 3 were pregnant. • 9 did not have a history of painful or distressing life events. • 3 were not inpatients during the study period. • 8 did not have gynaecological issues. • 4 only partially completed the survey. • Of the 14 who expressed interest via the QR code and were eligible to participate, 3 did not respond to attempts to contact them. • In summary, of the 47 potential participants who expressed interest in the study participated in interviews, 15 participated in interviews.

See Appendix 5 for the participants' profiles.

4.2 Key Themes

The data were analysed using reflexive thematic analysis, and through this process five themes and several related subthemes were identified. A summary of each theme is set out below:

- Theme 1: The health care setting is a very traumagenic environment especially for patients with endometriosis.
- Theme 2: Past distressing health care experiences shaped the views, expectations, and care-seeking behaviours of the participants in a range of different ways.
- Theme 3: There were many mediating factors which mitigated or exacerbated the risk of re-traumatisation.
- Theme 4: Most participants had learnt skills and knowledge to better manage their health care journey.
- Theme 5: Trauma screening should only be done if done properly.

4.3 Theme 1: The Hospital is a Traumagenic Environment

Although many research participants described their recent hospital admission in positive terms, the majority had experienced different forms of distressing experiences within hospital settings either at RWH or at other hospitals. Moreover, ***nearly all*** participants who reported past or recent distressing health care experiences, had an endometriosis diagnosis. Even more significantly, ***all*** those participants with an endometriosis reported having distressing experiences in health care settings during either this admission or previously.

The types of distressing experiences discussed by participants are grouped into different headings. They include dismissive or invalidating care where clinicians minimised their concerns or made assumptions about their health issues without a proper assessment; demeaning care (disrespectful, judgmental or dehumanising care), gaslighting (where clinicians attributed their health condition to psychological causes or made them feel as if they are exaggerating their symptoms), incidents within hospitals where they reported being assaulted or restrained, or medical treatment which had unexpected, lifelong and distressing consequences. Many of the participants also reported experiencing situations which had the potential to be distressing, due to them causing extreme feelings of powerlessness and vulnerability.

Nevertheless, even though many participants had negative or mixed health care experiences, nearly all of them highlighted how the genuine and attentive care relationship with clinicians, (particularly nursing staff, but also doctors and social workers), mitigated a lot of the negative aspects of their care experience and helped them feel safe and cared for. Moreover, most of the participants who had good experiences during their recent hospital admission also had an endometriosis diagnosis.

The different forms of distressing experiences are discussed in more detail below.

4.3.1 Dismissive or Invalidating Care – “Being Fobbed Off[3]”

Nine participants reported having experienced dismissive or invalidating care in either past or their most recent health care experience. This was a dominant theme for three participants and a minor theme for one other. Examples of dismissive or invalidating care included having health or pain concerns dismissed, clinicians jumping to conclusions without proper assessment or doing multiple redundant investigations

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[3] Jodie, 42

despite the patient insisting that these investigations were not needed. One participant referred to clinicians having "tunnel vision" (Priti 36):

> I went to the Royal Women's hospital emergency twice, both times they didn't take me seriously. They just did a pelvic exam. They knew I was in obvious pain. That's it. Once they offered an ultrasound, didn't even contact me with the results of the ultrasound. That's it. That was the end of it. The pain result for two months, but then I ended up collapsed on the floor. Um, so, I don't know. It was pelvic pain. They were going through the usual diagnosis, which is things like pelvic inflammatory disease. They were trying to make my symptoms fit into a box and when it didn't, I felt like they just didn't want to deal with it. Um, like you know, for instance, to do extra investigations and things like that. **Priti, 36**

A few participants went to great lengths to communicate their particular health needs to their care team, so having this information ignored or not passed on caused additional distress. For instance, one participant, who volunteered that he has PTSD, communicated his needs to his care team to reduce the risk of re-traumatisation. However, despite telling his care team that touching him without warning would be triggering for him, this information was not passed on, resulting in him becoming distressed:

> So, I came in for the procedure I was having, and I was very upfront with three different people going through the check-in process that I need more communication than they might be expecting because of my trauma history. And I demonstrated to the girl who was doing the, the checks at the start. Like, it's no good going, "I'm going to grab you now". I need

> you to go, "I'm going to grab you now". And then to the communication needs to come first. And then the action, you need to tell me you're going to be touching me before you are actually touching me. And she was very clear that she was going to pass that on. And I still told the surgeon and the surgeon's assistant as well and then they, they really didn't follow through on that. **Archer, 31**

4.3.2 Demeaning Care

Nine participants had experienced demeaning care in the past, while three experienced demeaning care during their most recent admission. Demeaning care involved care which felt dehumanising, judgmental, or the patient's express wishes were ignored. For example, Priti,36, who disclosed a history of family violence and reproductive coercion reported that she was not acknowledged by the clinician conducting an internal examination, and the clinician conducted the examination roughly. She also observed the clinician complaining to the nurse about the fact that she had to see additional patients:

> Before she performed ultrasound, there was no politeness, nothing nice, very ice cold. She just stuck the device in me, just moved it around without so much as a warning, like I'm going left or right. No words spoken at all. Um, and after she did it, I was actually even nervous to speak to her, and then I asked her like do I need to continue fasting? She simply said to me that something you have to discuss with your doctors, nothing else. **Priti, 36**

Another participant reported a past health care incident where he was asked extremely inappropriate and intrusive questions about his gender:

> a nurse at the Royal Women's Hospital in the past who I came in and she asked me who do I have sex with? What do my parents think about this? What's my childhood like? Am I going to get a penis someday? What are my thoughts on this, this, and this? This has been in the news. At the time when I met this nurse, I was feverish and I was not really able to, not, like, I just sort of responded and I gave all of these answers because I was in an altered state, and I was feverish, and I had an infection. **Elliott, 25**

4.3.3 Clinicians Attributing Psychological Reasons to a Person’s Health Concerns

“Medical gaslighting” came up as a subtheme of demeaning care for five participants. It was a dominant theme for one participant and a minor theme for four others. Medical gaslighting is when a clinician attributes psychological or social stressors as the reason for their health or pain concern, alluding to the fact that the pain is in their “head” or the result of their mental health issues.

Stephanie, 28, who has endometriosis, talked about an incident where she attended hospital after her legs “stopped working”. The doctor suggested she go on anti-depressants and alluded to her being in an abusive relationship with her partner who was standing next to her:

> And then he came in and just made all these big assumptions without assessing anything without, you know, I know there's ways you can check if someone's in an abusive relationship without saying that like, you know. And then saying like “mood stabilizers” as well, like I've not heard anyone call them mood stabilizers. I felt like he was calling me hysterical. And so, I started crying because I was like, “this is crazy”. Like, this feels

> crazy. And he said, “see, I just mentioned them and she's crying already”. And I was like, oh, it was just the moment. Like I could not have dreamt up a worse scenario, you know, like he said, “she's just depressed” knowing that I have a condition. And then said, “look, see she's crying so we should just whack her on these drugs.” **Stephanie, 28**

4.3.4 Assault or Physical Restraint

Three participants reported having been assaulted or physically restrained during past hospital admissions. For instance, one participant talked about being assaulted at another hospital by another patient, while one participant reported being restrained and removed from the hospital by a security guard. Another participant reported that she was restrained to the point that she nearly suffocated. Charlotte, 22, described an incident where she was assaulted by another patient:

> I'd had an experience in a stay at a different hospital earlier this year in which I was in a multiple bedroom. There was only two of us in there, but the other patient was very unwell, at least that's what I have to put it down to, and I got attacked when in that room. It took after me pushing the call button repeatedly and the fact that the room was right next to a nurse's station, it still took around 10, 15 minutes before anyone even stuck their head in. **Charlotte, 22**

Amanda, 28, talked about a distressing experience where she was restrained resulting in her nearly being suffocated:

> I had a very traumatic experience where I was sedated and restrained and almost suffocated as a result. It can be very stressful to be in that kind of an environment. And I think it's important that healthcare professionals

> are able to sort of approach your care in a way that puts those kinds of stresses at ease. **Amanda, 28**

Finally, Taylor, 23, talked about an incident where the doctor initially attributed psychological reasons for her health condition, and when she became distressed, she was removed by security:

> I did actually try to take legal action against one doctor in another hospital, but I couldn't because I didn't record anything. I didn't have any evidence. Basically, he just said, “I don't think you have pain. I think you need to see a psychologist, blah, blah blah.” I've been diagnosed with chronic pelvic pain, chronic illness, endo, cysts, lesions, all this stuff. It's physically there that I have pain and then he wasn't an actual doctor. He was, sorry, but he wasn't a gynaecology doctor. I said, “Can you just wait to speak to a gynaecologist for, you’re not helping”. Then, he started yelling at me and I had a panic attack because he was a huge man. He was like six foot tall. I was sitting in my little bed in pain, had a giant panic attack. Then they actually got me dragged out by security because they said I was causing a commotion because I was having a panic attack asking him to leave (laughs). Specifically, because of that one incident, that's why I have so much fear with hospitals. **Taylor, 23**

4.3.5 Other Forms of Distressing or Potentially Traumatising Experiences

Ten participants shared other examples of recent or past distressing experiences or situations which made them feel powerless, vulnerable, anxious, or scared. This was a dominant theme for three participants. For instance, Suzanne, 39, who had disclosed the incident where she had been restrained, said that during her recent hospital admission she was held down whilst coming out of anaesthetics which brought back distressing memories of being restrained. She also reported that not being warned about the fact that she would not be able to mobilise after her surgery was very distressing:

> But as I said, just the mobilization. If somebody's going to be in a position where they can't do anything for themselves without getting up, you need to tell them that that's going to happen. **Suzanne, 39**

She went on to talk about how she did not feel prepared for the large number of people she came across during her hospital stay, and how overwhelming this was, particularly when she was taken into surgery:

> It is a weird disconnect because once they actually took me to the theatre, which is odd here because they walk you into the theatre, they don't gurney you in, which is like what you kind of normally chucked on a table. And I guess you wait in a corridor somewhere and five different people come past, I don't know whether they're doctors or orderlies or graduates or who they are, but tons of people come and look at you and eventually one of them pushes you into an operating theatre. But here they walk you in. And that was when the care, that was when the concern kicked in **Suzanne, 39**

Another participant, Tanya, 33, who volunteered information about being a victim-survivor of a sexual assault, reported feeling sick and disorientated and “out of it on meds” due to the pain medication she was given. She reports this feeling, combined with not being told what was going on made her feel very scared. Finally, Meredith, 78, talked about a surgery being performed which had unintended but life changing consequences:

> I went back to the doctor and the GP said, “Oh, to stop your nagging,” those were his words, “I'll send you to a specialist.” I was sent to a specialist, but I had a biopsy at first. The biopsy doctor said, “Oh look, all you need is …um, some stitches in this. You're lucky you've just, it's a bad one, but you caught it in time.” But I went to hospital, and he said, “The doctor that your GPs chosen is a bit of a knife man, make sure you tell him all you want is stitches.” The specialist saw me and said, “I want to operate straight away, this is dangerous.” But I said to him, the biopsy said I only needed a couple of stitches. Oh. He said, “You don't know until we look inside because it's a bit like an iceberg.” And…. I had the operation woke up after it with this cast over my leg and the doctor bending over and saying, “I really wanted to amputate, but you hadn't signed the form.” So, I've got a big piece out of my leg. And I don't know who was right. Then when I asked about my records, they were lost at the hospital. **Meredith, 78**

Meredith shared that as a result of this incident, she needed a much higher level of accountability from medical teams caring for her.

These findings are in line with other studies which maintain that patients who have experienced distressing or traumatic life events experience high levels of re-traumatisation within the health care system (Raja et al., 2015; Reeves, 2015; Reeves & Humphreys, 2018; Schroll et al., 2013). Having health practitioners dismiss pain concerns is also a central theme in other studies (Price et al., 2006; Ross et al., 2023).

While repetitive redundant testing, being belittled or told that symptoms are all psychological are all forms of dismissive or distressing health care experiences identified by participants in the study by Ross et al. (2023). Other studies highlight how medical professionals are more likely to attribute psychological reasons for pain when caring for female patients (Hoffmann & Tarzian, 2001, p. 14)

According to participants in studies conducted by Raja et al. (2015) and Reeves (2015), incidents such as being restrained, disorientated, or trapped and immobilised can serve as reminders of past abuse, while fear of being unconscious or touched are concerns identified by participants in the study by Raja et al. (2015). Furthermore, Reeves (2015) highlights how having too many practitioners in the room can trigger a response in people with a history of trauma. These are all ways in which a person's sense of safety can be affected.

Finally, a few of the participants experienced, what Freyd and Smith (2014) call "institutional betrayal". According to Freyd and Smith (2014), "institutional betrayal" happens when people are let down by the very systems and institutions which are supposed to protect them. Being let down can result in further traumatisation. This was the case for Archer, 31, who warned multiple members of the care team to not touch him without telling him first, but then this information was ignored or not passed on to everyone.

4.4 Theme 2: Past Health Care Experiences Shape Present Day

Past negative health care experiences influenced the views, expectations and health care seeking behaviour (in both negative and positive ways) of most of the participants. The ways that views, expectations, and behaviour is affected is discussed as follows:

4.4.1 Past Health Care Experiences Shape Views and Expectations

Past health care experiences shaped the views and expectations of most of the participants to some extent, but for six participants, this was a dominant theme. For example, many participants such as Suzanne, 39, reported having low expectations because of her past negative care experiences:

> But in what I want to say as well, it was distressing, but it was also what I expect from a hospital experience. So, while I was upset, I was still resigned to it because that's kind of what I, it's not unlike what I expect.
>
> **Suzanne, 39**

On the other hand, many participants, particularly those with endometriosis diagnoses, highlighted how good their admission at RWH was in comparison to past negative health care experiences they had had either at RWH or elsewhere. For instance, one participant, who had a lot of experience having her pain concerns dismissed in the past, talked about having low expectations but being pleasantly surprised:

> You come in with, from my view, you come in with particular expectations and you think are they going to be met? and you've got to not let yourself get worked up on that because it's not completely surprising. It's not the right thing to say. Cause I know that it's a good hospital. Um, but I didn't know what to expect with care. I just thought I'd get the same sort of care if not than what I got elsewhere. Cause I knew, it was a public hospital there was a lot of people in there and that sort of thing, but I just, I was really pleasantly surprised at just how smooth it went. **Lyndsey, 46**

Taylor, 23, reported that she had had negative health care experiences elsewhere so came to RWH because it was recommended to her, while Priti, 36, said that because she had had such positive experiences of care at RWH in the past, she chose to return there when she had a burst cyst; however, when she did return, her experience in the emergency department was very negative:

> Interestingly enough when I had this pelvic pain, my GP told me to get an ambulance and go straight to XX hospital, but because I have such a good positive association with Royal Women's hospital, I didn't take her advice and I went to Women's and I regret it because the care at the emergency department was well below the standard of everywhere else in the hospital that I experienced. **Priti, 36**

4.4.2 Past Health Care Experiences Shape Health Care Behaviours

Many participants talked about being scared to go into hospital or avoiding care due to negative experiences. This was a major theme for two participants and a minor theme for another three:

> I've just had things like, medical gaslighting they just, things like, because I'm asking for pain medication, they think that you are just like you're dependent on pain meds, which is quite normal reaction from doctors when you have like a chronic illness and things like that and chronic pain. Um, so, no, I've just had a lot of like you know, I put off going to the hospital for five days. I was in agony for five days because I have too much anxiety and fear with hospitals because of how I’ve been treated.
>
> **Taylor, 23**

One participant who had a distressing experience in hospital was worried that her care would be affected if she made a complaint while a few others discussed how past negative health care drove their need for accountability or an advocate to support them during their health care journey.

Moreover, some participants went to great lengths to reduce the risk of further traumatisation through taking different forms of action, such as providing additional information about their particular care needs or triggers or bringing a partner or "fake husband" to support them. For instance, Archer, 31, got an infection post-surgery but contacted the emergency department to see if he could avoid going into hospital because of the distressing health care experience he had had whilst an inpatient:

> Like when I had to come back last week to the emergency room, I did actually call ahead to try to find out if I could get away with not coming back (laughs). I called ahead to try to find out if I could get away with going to a different hospital or a different emergency room rather than having to come back to this hospital. **Archer, 31**

However, when Archer (31) did come back into hospital, he brought in communication aids to try to reduce the risk of him being re-traumatised:

> And I have little enough faith in our hospital system and communication that I actually took a whiteboard with me to that hospital with a marker so that I could put like "warn me before touching me" on that whiteboard and leave it like on my bed where people would see it before they approached me. Like that, that that's the level of faith I have in the hospital system. **Archer, 31**

These findings align with other studies which contend that individuals with a history of trauma often view the world as dangerous and untrustworthy (Kezelman & Stavropoulos, 2012, p. 50). Many trauma specialists describe how individuals with symptoms of trauma, such as chronic hyper arousal and hypervigilance, often spend a lot of time waiting for something negative to happen or go wrong and use avoidance behaviours as means to cope (Rothschild, 2000; Herman, 2015; Van der Kolk, 2014). McGregor et al. (2010) also highlights that patients with a history of trauma are acutely sensitive to situations where they feel vulnerable or where there is a power imbalance, which increases their level of fear and anxiety when coming into health care settings.

4.5 Theme 3: Several Factors Mitigate or Exacerbate Risk

There were several factors which helped mitigate or exacerbate the risk of individuals being triggered or re-traumatised. These have been grouped into the following subthemes:

- The health care environment
- The quality of communication, consistency, and integration of care
- The care relationship
- The role of support

4.5.1 The Health Care Environment

The health care environment had both a positive and negative impact on many of the participants' health care experience. Environmental factors were a major theme for one participant, and a minor theme for two others. Many participants talked specifically about the impact of environmental factors and privacy on their care experience. For instance, two participants talked about how noise and being interrupted during the night affected their sleep, while another participant talked about how overwhelming it was to be confronted with multiple people during their health care journey.

Privacy was particularly highly valued by three participants who had had previous medical trauma or experiences of their safety or psychological safety being violated in health care settings, for instance, one participant was scared to go into hospital due to her past experiences of medical gaslighting and being removed from hospital by security; she saw privacy as being integral to her psychological safety:

> Um I got put into my own actual room, with the door and everything, which that just really helped to ease my anxiety so much because I didn't have to deal with all these bright lights and people crying and screaming and doctor's running everywhere and having no privacy to actually be able to deal with my pain. **Taylor, 23**

Furthermore, Charlotte, who had been assaulted by a patient at another hospital, could not mobilise after her surgery, so being in a private room made her feel safer:

> I suppose something that would've gone along with the physical safety, but also the psychological safety as well. This may sound ridiculous, was largely in part due to the move to a single room. Because I'd had an experience in a stay at a different hospital earlier this year in which I was in a multiple bedroom. There was only two of us in there, but the other patient was very unwell, at least that's what I have to put it down to, and I got attacked when in that room. **Charlotte, 22**

4.5.2 Quality of Communication, Consistency, and Integration of Care

4.5.2.1 Preparedness: Telling You What to Expect Helps Prevent Medical Trauma

Most participants talked about the importance of being told what to expect as a way of reducing the risk of distressing experiences occurring. This was a dominant theme for two participants and a minor theme for one other. For instance, Charlotte, 22, who had disclosed being assaulted in a hospital, knowing what to expect and knowing when the nurse was going to come helped ease her anxiety:

> I knew everything was coming and roughly what time of the day to expect as well with things like with those ones. That helped me feel a bit more at ease as far as that went. Because things like that, I knew what was coming, I knew what to expect. For me, that's a very important thing when you know what to expect and when to expect it makes you feel a bit safer, a bit more comfortable with things like that. **Charlotte, 22**

Furthermore, Suzanne, 39, highlighted how empowering it was to be given information on what to expect:

> It's very empowering to know what's going to happen at every step. And that's what I was saying, nurses do that to you because they recognise that about the process, and I guess it probably makes their job easier too because then you don't have patients calling you every two seconds because they know what's going on. **Suzanne, 39**

4.5.2.2 Valuing Clear Communication, Timely Care, and Continuity in Care

Clear communication systems, continuity of care and timely and responsive care were very important to many of the participants. The importance of having good communication systems was a dominant theme for four participants and minor theme for three others. The importance of timely and responsive care and continuity in care were dominant themes for four participants. For instance, Tanya, 33, had to have emergency surgery for a twisted fallopian tube. She talked about how a lack of continuity of care increased her fear and anxiety:

> Just consistency. It's freaky when you're in hospital and everyone coming in to help you is different every time. Like it's really unsettling when you're feeling sick and you're feeling scared about what's happening.
>
> **Tanya, 33**

She compared her care at RWH with her care at the hospital she initially presented to before being transferred:

> I'm just contrasting it with XX hospital, which was *amazing*. Where I first went like they would come in and say, "I'm the doctor taking care of you. This is me. This it's going to be me". It was the same person until they said, "I'm handing over now it's going to be this next person" and same with the nurses they'd say, "I'm taking care of you". **Tanya, 33**

4.5.2.3 Viewing Care as "Random and All Over the Shop[4]"

Seven participants viewed their recent care experience as "random and all over the shop" (Tanya, 33). This was a dominant theme for five participants and a minor theme for two others. A few of the participants felt that they were not prepared for what to expect and that hospital processes did not prepare them for the actual procedure, or that health practitioners consistently did not do what they said they were going to do.

A few participants reported that important information about their care needs was not passed on. Some participants also talked about how they did not really know

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[4] Tanya, 33

what was going on or were not updated during their hospital admission while others talked about having to wait long periods for their buzzer to be answered. Having multiple people come into their room without introducing themselves was a major theme for two participants.

For instance, Tanya, 33, reported a lack of continuity of care in that she did not know what was going on, and care providers coming into her room would not introduce themselves or their role:

> When I was in emergency…... I felt like there was different people coming in there felt like there were long periods I was left alone. I wasn't getting as much info. **Tanya, 33**

She went on to describe how nauseous the pain medication she was given made her feel, but despite repeatedly asking why for an explanation for why her nausea was so bad, she did not receive any reassurance or explanation. She reported that since being discharged from hospital, nausea, even when there is a clear cause, makes her feel very anxious.

Moreover, Suzanne, 39, highlighted how she felt unprepared for what to expect, resulting in her feeling distressed when faced with many people in the anaesthetics room, and coming across multiple people throughout her health care journey was also overwhelming and stressful:

> What you're not prepared for when you come into hospital is the amount of people you come into contact with who will just literally wheel you one way wheel you another way you won't know who they are, what they're doing, what their role is. You would probably, I'd say in the whole process, like 20 people, 30 people, that's a lot of people to be bombarded

> with. And half of, most of the time you don't know who they are or what they're doing. **Suzanne, 39**

Suzanne, 39, who disclosed a past distressing incident where she was restrained and nearly suffocated, goes onto to talk about how she was not prepared for the possibility of needing a drip. At first, she thought this would restrict her movement and make her bedbound. She reports that she had had a lot of therapy due to her trauma history, otherwise she would have been far more distressed by this:

> As I said, don't assume people know what a drip is. It just didn't connect. I had a lot of stuff going on in the weeks leading up to this. It didn't connect that that was the thing that I'm not going to be able to move myself. When people's movement is restricted it's like as soon as somebody can't move and their own volition, that's where you have to start thinking about it because as soon as somebody can't go anywhere, that's an immediate trigger for distress. Immediate. **Suzanne, 39**

Lauren, 33, talked about how a lack of integration in her care resulted in her not finding out the results of a scan until weeks later, and then she talked about being “blindsided” when what occurred at the post operative appointment was completely different to what she had been led to expect. As mentioned earlier, Archer, 33, who disclosed having PTSD, talked about how he provided a significant amount of information on his individual care needs to the care team, to reduce the risk of triggering, yet this was not passed on to appropriate people.

The concerns shared by the study participants are like those found in other studies. According to De Lima, Shatell (2005), Ulrich et al. (2008), and Williams et al (2008), noisy, overstimulating environments can often make patients feel limited control over their own bodies and dependent on others for care; as such, communication and reassurance are important to find a sense of control when their sense of autonomy is feeling compromised.

These study findings are also similar to the conclusions made by O'Brien et al. (2007) and Purkey et al. (2018), who found that continuity of care and the nature of the physical space help ease the anxiety of patients with a history of trauma.

4.5.3 Quality of the Care Relationship: Authentic, Validating, and Individualised Care

The importance of the caring relationship was a dominant theme in the research. Participants distinguished clinicians who just did their job to those who went out of their way to help. Genuineness in the care relationship was highly valued. This was closely aligned to the importance of being treated like an individual and not just a number. Participants described how vulnerable they felt being dependent on others for their care, and feeling scared that they will be forgotten about.

A quality caring relationship appeared to mitigate the impact of potentially traumatising events on those occasions where participants were confronted with challenging and frightening situations. The importance of consent being ongoing and not one-off was also highlighted by some participants. These different aspects of care have been teased out into six sub themes; however, in reality, these subthemes often overlapped.

- The difference between just doing your job compared to going out of your way to help.
- The relational aspect of care and being cared for by women.
- Looking out for and noticing you.
- Consent each step of the way.
- Having acknowledged agency in your care.

4.5.3.1 The Difference Between Just Doing Your Job Compared to Going Out of Your Way to Help

Many of the participants distinguished clinicians who appeared to just ask routine questions from those who really wanted to know. This was a dominant theme for four participants and a minor theme for two others. Trust came from feeling like they were an individual, not just a number. Having individual differences recognised and health care concerns taken seriously were consistent themes for these participants. This point was highlighted by Stephanie, 28, who valued clinicians who viewed her "as a person as well, and not just as a condition".

Priti, 36, who disclosed a history of family violence and reproductive coercion held the view that patients would not volunteer sensitive information or disclose family violence unless the clinician appeared genuinely interested in knowing. She distinguished "meaningful questioning" from what she referred to as a "tick box exercise". The importance of taking information seriously was also highlighted by Taylor, 23:

> They weren't just ticking boxes with my answers. They were writing down full things of what I was telling them. They weren't just going, "Do

> you have this? Yes. Next question. Yes or no." They'll be very personal with it. ***Taylor, 23***

Another participant, Archer, 31, wanted to remind clinicians that while coming into hospital might be routine for them, this is not the case for patients:

> I guess that I understand that this is their job and they do it every day, and that we are just like, you have like 10 people come in for the same procedure and it's one after the other, and it's routine for them, but it's *not* routine for us. It's a vulnerable position to be in. You're trusting strangers with your medical care and decisions, and it would be good to be a little bit less like, a number on a form and a body on a table a little bit more like a person. **Archer, 31**

4.5.3.2 The Relational Aspect of Care and Being Cared For by Women

Clinicians going above and beyond what they needed to, and being authentic in the way they treated patients was a theme highlighted by many of the participants. Stephanie, 28, refers to it as "going the extra mile", while Priti, 36, refers to it as "genuine care". This was a dominant theme for four participants and a minor theme for two others. Many participants viewed clinicians (nursing staff in particular, but also doctors and social workers too) as carers. They highlighted the therapeutic value of this caring relationship. They also emphasised the way that feeling taken care of helped them feel psychologically safe and how the care relationship with nurses and other clinicians, mitigated the risk of re-traumatisation, particularly when distressing experiences occurred:

> Nurses make hospital bearable. They understand that inherently you are powerless, and you are scared, and you are thirsty, and you are hungry,

> and you don't know where you are. And things like that. It's like they just inherently understand that you don't want to be here and that you don't understand it and you're trapped, and they just make it so much they do everything that they can. **Suzanne, 39**

Four participants highlighted the fact that most clinicians were women and that this contributed to their sense of safety. For instance, Tanya, 33, who reported having experienced past trauma, had to have an internal examination; she believed that she would have been re-traumatised had the internal examination been conducted by a man:

> I think trust and confidence is linked to that feeling of feeling cared for, that someone's looking out for you and noticing and will be there and come if you need or whatever. I feel that more with women. **Tanya, 33**

While another participant, Priti, 36, who experienced past trauma including family violence and reproductive coercion, reported that the doctor conducted the internal examination very roughly and did not even acknowledge her during the examination. But she believes it was the care and support of the nurse who witnessed the incident and the rest of the nursing care she received when in hospital which stopped the experience from being any more distressing than it was and helped her feel both psychologically and physically safe:

> Their level of care was a big part of how quickly I felt better, not just physically, but also psychologically as well. I felt I was taken care of. I felt safe and I felt like I had my human dignity, which is something they take away from you when they're treating you very cruelly when you're in a vulnerable situation for the physical illness. Because of the nurses, I

> actually, it wasn't a horrific experience despite my physical condition. It wasn't a horrific, traumatic experience **Priti, 36**

4.5.3.3 "Looking Out For You and Noticing[5]"

The value of being checked on each step of the way, and updated, even when there is no news, and having clinicians who looked out for and noticed them reduced anxiety and stress were themes which came up for many participants. Participants described being scared that they had been forgotten about and needed additional reassurance due to this. This was a dominant theme for three participants and a minor theme for three others:

> I think that still just falls under being checked on regularly and knowing everyone who was on the ward and stuff. And knowing that if I had any concerns or anything they were going to be answered almost straight away. Because I have had experiences in the past with hospitals where I've been admitted to bed, but sometimes I could wait hours for somebody to come and check on me after I pressed the button and then that just leaves me really stressed and anxious and stuff, but I didn't have that experience at the Royal Women's. So that's definitely helped. **Amanda, 28**

4.5.3.4 Having Acknowledged Agency in Your Care

For the participants, acknowledged agency meant being believed, having their concerns acknowledged and validated, having clinicians validate their expertise and efforts to manage their own health, and recognise the emotional impact of chronic illness and hospitalisation. The importance of being treated like an active participant in

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[5] Tanya, 33

care was highlighted in this subtheme. This was a dominant theme in six of the participant stories and a minor theme in three others. These participants wanted clinicians to ask them for their opinion instead of just telling them what to do and wanted to figure things out together with their clinician. A minor theme for three of the participants was that they wanted clinicians to recognise the emotional impact of living with a chronic health condition:

> Yeah, at no point, like I've been going to The Women's for five years for this almost. And I have no one said like, "how's it going?" You know, like I haven't worked three years because of this, and no one said, "how's your mental health?" You know, and I've got a psych and they're amazing. And you know, I took all of that upon myself, but I was like, gee…surely at some point someone's going to be like, are you depressed yet? Because this is a bit, you know. **Stephanie, 28**

4.5.3.5 Consent Each Step of the Way

Many participants highlighted the point that consent should not be assumed, and just because a person consents to hospital treatment does not mean they are consenting to everything. The importance of needing to seek consent at each step of the clinical journey was an aspect of acknowledged agency and came up as a minor theme for four participants. This concept was also referred to as "overall" consent by Stephanie, 28, and as "micro-consent" by Archer, 31:

> Like, you know, you come into a hospital, there's a lot of *assumed consent* because you are there for a procedure and there's things that are involved in that procedure and they will just do things to you without talking to you about what's happening. And I don't like that…. And just

> because you've consented to being there today doesn't mean they don't need your permission to be manhandling you or touching you. **Archer, 31**

One participant, Lauren, 33, raised the point that consent is meaningless if it is given under pressure. She discussed an incident when she felt she could not say no when a male student doctor was allowed in the consulting room:

> There was another student in the room, a male student, and I kind of thought (laughs) it would've been good to have a heads up on this or even like, have my permission ahead of the appointment, not in there in person. Like, I can't say “no” to someone's face. Like, “no, I don't want you here”. **Lauren, 33**

4.5.4 Having Support “When Going Through Really Big Stuff[6]”

The importance of having support when going through health-related difficulties was a minor but notable theme in that it came up for more than half of the participants. It was a dominant theme for two, and minor theme for six participants. The type of support valued was different for each participant and included the following: having an advocate or a witness, having community support, emotional and social support.

Having an advocate or a witness helped increase a sense of accountability in care and ensured concerns were heard and valuable information was not forgotten; having peer support from someone within the community helped reduce a sense of isolation and provided access to valuable sources of knowledge and information; having emotional support helped participants get through the challenges and stress of the hospital environment and living with a chronic health condition, and social support

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[6] Stephanie, 28

could be both financial and practical. For many of the participants, a support person fulfilled more than one role.

4.5.4.1 Having an Advocate, Witness or a "Second Set of Ears[7]"

Four participants recognised the importance of having an advocate or witness. The role of witness was seen to increase clinician accountability and help ensure nothing unsafe occurred during the health care interaction. Advocates also helped ensure the individual's health care needs were taken more seriously and that they were believed:

> I had appendicitis once, but they thought, and this is when I was around 20, so not long after I'd been diagnosed, I had appendicitis and they said, "Oh, it's just endo". Then I went back in twice because my mom basically yelled at them until they did an ultrasound, and my appendix was about to burst. **Taylor, 23**

Advocates also acted as a "second set of ears", especially for participants who struggled to take in information due to medication or stress:

> it was also great that each doctor that came by it was usually the same doctor, but each time he was willing to wait before he started, he used to wait for me to get, say for example, my dad on the phone to have a second set of ears to hear everything that was going to be explained. Because obviously that early in the morning when you're being given loads of medication, loads of pain medication and everything like that, things tend to be a little foggy. **Charlotte, 22**

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[7] Charlotte, 22

Two participants reporting being supported by social workers during their hospital stay and the benefit of this form of support to help them navigate the health care system. Moreover, two participants said that it was important to have a “fake husband” to be believed:

> It's a bit distressing because I know that the general rule that everybody that has these conditions, if they don't have a husband, they bring a fake husband who just generally doesn't have to say anything. He's just an observer. And you get treated remarkably better when they're in the room.
>
> **Suzanne, 39**

One of the participants, Taylor, 23, reported that she prefers not to go to hospital on her own due to her fear that she will be treated badly or not taken seriously. As such, her partner usually attends hospital with her:

> They treat you so differently when you have an advocate there because it's almost as if they don't care what I'm saying but if someone else that isn't in pain and isn't attention seeking is confirming what I'm saying, then they'll listen to you which is just ridiculous. But realistically, that's most of the time that's always that works. You need to have someone else there who's not in pain and who's not crying, and he is basically normal in a way for them to say, “No, I can confirm like this is a problem,” and then they'll listen to you. **Taylor, 23**

Another participant, Meredith, 78, had experienced past medical trauma when she had surgery for removing a mole which resulted in her nearly having her leg amputated. She talked about accountability being important to her care, such as having more than one doctor treat her:

> At the Royal Women's, when I first went in for my appointment, I had one doctor and then she said, “Do you mind if I go and consult my colleague?” And, um, they were looking at me with their speculum. It's not the most pleasant thing, but two of them worked on me for a while and I heard them talking and I thought, “I'm lucky there are two people looking at me, not just one”. **Meredith, 78**

4.5.4.2 Having Peer or Community Support

One participant reported being part of the broader LGBTQI community, while four reported being part of the endometriosis community. These communities were sources of education, emotional support and information sharing to these participants:

> Yeah, I've got a few support groups. I’m in five or six different Facebook groups. I made a lot of online friends over the last few years from it that I speak to on a daily basis. That's honestly where you get most of your support from. **Taylor, 23**

4.5.4.3 Having Emotional Support

Three participants identified the value of having good emotional support and someone to talk to when dealing with challenging medical situations or having to make potentially life changing decisions:

> I was often taking either a parent or a partner with me because we were dealing with really big stuff and especially the removal of my ovary. I didn't know if they were going to take everything out and that they're really big things to be managing like, you know, from 24, 23. **Stephanie, 28**

While another participant used the term “hand holder” when describing the importance of a support person to sit with them when waiting for appointments and help them manage their anxiety.

4.5.4.4 Having Good Social Support

Finally, three participants viewed good social support as critical to living with a chronic health condition, while two others valued having the financial support from their partner:

> If I didn't have the support system, I had then I'd have been diagnosed with depression, anxiety and that is really because of my pain. If I didn't have that support system, I would just be really down all the time. I have like major depression 24/7. So, I can just imagine how much harder it is for people that don't have anyone there to help them or anyone to look after them. **Taylor, 23**

These findings support existing literature on trauma-informed care. Elliott et al. (2005) highlight the therapeutic aspect of the relationship between clinician and patient, as central to developing safety and trust (Elliott et al., 2005). Elliott et al. (2005) also view health care which is validating and empowering and care which emphasises resilience over pathology and collaboration over medical “expertise” as central principles of trauma-informed care (Elliott et al., 2005).

Ross et al. (2023) and Reeves (2015) also placed emphasis on the relational aspects of care and the importance of having a support person. The importance of having choice over the clinician’s gender is also a finding identified in other studies (Reeves, 2015; Ross et al., 2023; Schnur et al., 2018).

Moreover, the important role of acknowledgment and validation was also highlighted by McGregor (2013) and Sobel (2018), and the importance of being checked on regularly was highlighted in several other studies (McGregor et al., 2010; Raja et al., 2015; Sobel et al., 2018). Finally, the importance of consent being ongoing, acknowledging patients' agency in their health care decisions and having expertise recognised and acknowledged by clinicians is highlighted in some studies (Reeves, 2015, pp. 701-703).

It is important to highlight how quality communication systems, consistency, and integration in care overlap with quality and genuine care relationships. Clear and transparent communication and consistency in care are important aspects of a quality and genuine care relationship, however, quality care is *more* than just good communication. It is *more* than just "doing your job" or "routine care". In the words of the participants, "going the extra mile", "looking out for and noticing you" and "genuine care" hint at how important the relational aspect of communication is to individuals with a history of trauma.

4.6 Theme 4: Learnt Skills and Knowledge to Better Manage Health

Despite the prevalence of triggering or potentially traumatic health care experiences amongst the study group, most participants described strategies they had learnt overtime to better manage their health care; they also showed high levels of health and mental health literacy which likely helped them better understand their health and mental health needs and self-advocate to have these needs met.

Moreover, many participants had engaged in a lot of healing and were able to view their care experience from a place of distance. These patients used their stories as a tool to advocate for change, and viewed their care experience through a political, structural, or feminist lens. This theme has been separated into subthemes; however, many aspects of these subthemes overlap.

- Becoming an expert.
- Reflecting on their chronic health journey.
- High level of health or mental health literacy.
- Viewing care from a place of distance and using their story as a platform for change.
- Viewing care through a political, structural or feminist lens.

4.6.1 Becoming an Expert: “Having to Pave Your Own Path[8]”

A significant subtheme which stood out was the level of skills and knowledge many of the participants had developed over time to better cope with managing chronic health conditions or challenging health care environments. This was a dominant theme for five participants and a minor theme for four participants. Participants discussed strategies they had developed to help manage being in hospital, or knowledge and experience they had developed to cope with a chronic health condition.

Lorraine, 60, who has many allergies and multiple health issues, has had to learn ways to manage her health, while in hospital:

> I've got folders here with it that I've highlighted different things and I've had so many MRIs and ultrasounds and that they don't give you access to that information and that portal and all that I can get from there is my blood tests. I want more information. I want to have access to; most people don’t care but I do. I want to see what the MRI has shown. I want to see what the ultrasound showed. **Lorraine, 60**

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[8] Stephanie, 28

Lorraine also spoke at length about the skills and knowledge she developed to cope with her long hospital stay (18 days):

> So, I had these signs that I made up and I'd put them on the door. Then eventually the doctors said I wasn't to be disturbed through the night at certain times either. If I could try and get it. I tried working with everybody when the catering was coming, when this was, and I knew the schedules when the changeover was coming. I put on my sign "resting, so please don't come in" just to try, if I hadn't slept through the night, an hour or two. **Lorraine, 60**

4.6.2 Reflecting on the Chronic Health Journey

For some participants, an aspect of "becoming an expert" was their ability to reflect on their chronic health journey. This was a dominant theme for two participants and a minor theme for three others. Five participants saw their condition as chronic and talked about the challenge of coming to terms and living with a chronic health condition:

> I kept waiting to, I often refer to like wanting to go back to the person I was, I kept being like, "I'm going to get back to her", you know. "I'll have the next surgery and then I'll get back to who I was". And it took me a long time to realize that, you know, this health condition was staying around, and my life didn't look the same anymore, **Stephanie, 28**

Themes of grief and loss, the financial impact of living with a chronic health condition and not being able to work came up for some of these participants, while the impact of pain and pain medication on quality of life also came up for others:

> I could have a birthday coming up in three months and I'm already thinking about, well what's my excuse going to be if I'm in pain? Because I don't want them to know I'm in pain. It really does ruin your quality of life in a way. **Taylor, 23**

4.6.3 High Levels of Health and Mental Health Literacy

Many of the participants had high levels of health or mental health literacy. This was particularly the case for some of the participants who had endometriosis. For instance, Stephanie, 28, talked about her journey of learning how to manage her health condition:

> I've had to pave my own path with my pain management, and I've gone and found physios and done, like, I've done all the research to get this amazing team happening, but…. And doctors are often shocked by that because I have all this knowledge about, you know, pain management, but I've had to work that out myself. **Stephanie, 28**

4.6.4 Viewing Care Experience From a Place of Distance and Using Their Story as a Platform for Change

While some participants reflected on their chronic health journey, others viewed their care experience from a place of distance and used their story as a tool for change. For many participants, this was another aspect of “becoming an expert”. Half of the participants had engaged in some form of healing and were able to reflect on past distressing health care experiences from a place of distance. Some participants explained how potentially traumatising experiences did not impact on them to the extent that they could have because they had engaged in different forms of self-help. For instance, eight of the participants had done therapy or accessed other forms of support over the years and attributed this to why they were able to better cope with hospitalisation:

> Look, I've done a lot of therapy on it, so I don't like completely flip out anymore, but generally speaking, I shut down a bit, so I go quieter, which again, most doctors take as compliance rather than anxiety. **Archer, 31**

There was also an element of giving back to the community for many of the participants. Many participants saw themselves as speaking on behalf of the endometriosis community, this was a dominant theme for two participants and a minor theme for three others:

> And it's the kind of thing that like, obviously you're talking about this specific period in a stay, but it's the kind of thing that …. these kind of research studies, the endo community wants to be part of so badly. **Stephanie, 28**

Many of the participants, particularly those with endometriosis, the majority of whom had had past distressing experiences in hospitals, wanted to champion the fact that they had had such a positive health care experience at RWH. This was often in response to the fact that they had had such negative experiences in the past (either at RWH or elsewhere). As such, they saw the research study as a way of championing the hospital and health practitioners:

> It exceeded all of my expectations. I think my negative expectations, it just, everything blew past those, I think like the things that I was really, really worried about. I actually, I printed out. I printed out a piece of paper with some explanations of things in case someone came to me and started asking inappropriate questions. About what I would answer and

> what I wouldn't answer, and why, because it's happened to me before at the Royal Women's and other places. So, I was sort of prepared for the worst-case scenario, but it really didn't eventuate. Everyone was really, really good. **Elliott, 25**

4.6.5 Viewing Care Through a Political, Structural, or Feminist Lens

Many of the participants, particularly those with endometriosis, viewed care through a political, structural, or feminist lens. This was a dominant theme for three participants, and a minor theme for one. Political and structural issues were dominant themes for three participants while the issue of gender inequality was a dominant issue for one.

Two participants talked about being bounced from GP to hospital while two talked about the system being overcrowded. For example, Fatima, 31, talked about her experience of trying to access treatment for endometriosis:

> I ended up seeing my GP for that. And it was just like, why are you seeing me for, why aren't you going to the hospital like the hospital? And then if I go to the hospital in the emergency, they're like, your vitals are fine. Why are you seeing us? Why don't you go to your GP? So, the outpatient thing is very, is very depressing. There's no, no one I can go to, no one I can speak to. **Fatima, 31**

Lauren, 33, talked about how mistakes in the sequencing of some of her appointments meant she had to wait a long time for her appointment with the gynaecologist and when she did finally have the appointment, she was not prepared for the discussion, despite having access to the patient health information system. She wanted to see better integration of care:

> I do understand it's not always going to be like this magical one-stop-shop to fix everything. Especially if you've just undergone a surgical procedure and you're coming down off anaesthetics and meds. You can't now be tested for something in case it impacts those results. But I think that there probably is some room for like integrating these things. I just I but that's a, I know that that's a bigger systemic issue. **Lauren, 33**

Many participants viewed their care through a feminist lens. For instance, Tanya, 33, saw women’s health conditions as “women’s business” and did not believe male doctors should have decision making power over women’s bodies, while other participants expressed the view that women’s health issues are not taken as seriously as other health issues. The belief that chronic pain conditions such as endometriosis get treated differently was a recurring theme for four participants and to a lesser extent for one other:

> You think the fact that's as common as asthma and diabetes, that's how common endo is. You think that there'd be a lot more awareness on it. Um, but there's not, because asthma and diabetes affect both genders and endo affect obviously females. That's why they're like, “Well it's a female problem. We're not going to put this much investment into it.” It's only, like females and that's why, in my experience that's just why it's just so undereducated and it's very frustrating. **Taylor, 23**

The topic of women’s health was a central theme for Fatima, 31. She believed that women’s bodies and health issues are often pathologized and that there needed to be more research into alternative options for managing women’s health conditions. She went on to assert that standard options offered for the management of some women’s health issues, such as the insertion of a Mirena to manage pain, were used primarily as a cost saving exercise and not because they were good for women’s overall health, and their use should be reviewed:

> And back to the whole thing of like women's health, I don't think it's a priority in Victorian care. Like it'd never been looked at before. So, a woman missing a period is absolutely normal. Whereas like me coming in, it's shocking to hear a doctor say that. **Fatima, 31**

She went on to criticise the decision-making power that medical practitioners have over women’s bodies and critiqued the way that the medical system views the woman as a “body” rather than holistically. She believed that there are limited treatment options for conditions such as endometriosis and she felt that there needed to be more research into alternative options for managing many women’s health conditions than those currently on offer.

The idea of women being “hysterical” and how this reinforces existing gender stereotypes was also a minor theme for a few participants. For instance, two participants used terms such as “gas lighting” when referring to how doctors attributed their pain to psychological reasons, making them feel like it is all in their head or that their crazy. Moreover, Priti, 36, believed women are treated differently to men when it comes to pain:

> Like taking my pain seriously because I feel like often, um when women complain of pain, a pain they're not taken very seriously as opposed to a man complaining of the same pain. People seem to think that she's been dramatic or exaggerating. **Priti, 36**

However, while both trans participants had very different health care experiences in their most recent hospital admission, they both reported having experienced past medical trauma and spoke of situations where they felt invalidated due to their gender. One of the participants also reported having a lot of fear of hospitals due to community trauma experienced within the trans community:

> I understand that as a trans patient, it's a little bit more complicated for me to be receiving treatment at the Women's Hospital. And like there is added psychological difficulty in being a man, having to have a medical procedure at The Women's hospital. They did handle that side of things fairly well, like much better than the last time, honestly. But I think they got quite hung up on that and let the rest of it slip a bit. **Archer, 31**

On a more positive note, both trans patients mentioned feeling that RWH was becoming more inclusive in the care provided to gender diverse patients.

Trauma-informed care (TIC) focuses on empowering the patient, acknowledging, and validating their expertise, building on existing skills and knowledge, and encouraging patients to take ownership over their own health. It does this to reduce the risk of re-traumatisation and improve the overall health care experience of patients (Fallot & Harris, 2009). The findings show that many patients already take active steps to reduce the risk of re-traumatisation, using strategies they have learnt over time. The findings also highlight the importance of giving voice to the patient experience and incorporating their views and care preferences into organisational systems, which is in line with the TIC literature (Fallot & Harris, 2009).

The concept of recovery from trauma, through engaging in stages of healing and recovery was a dominant theme for many of the study participants. This is a view supported by the author Judith Herman (2015), who views healing, remembrance, and mourning, meaning making, testimony, reconnection, and social action as some of the stages of recovery from trauma. Herman (2015) sees therapy and engaging in group work to share knowledge, build connection and reduce isolation as part of the healing process. Using opportunities such as research and peer support groups such as endometriosis support groups as ways to share your story and advocate for change can all be viewed through Herman's recovery model (Herman, 2015).

4.7 Theme 5: Trauma Screening Should Only be Done if Done Properly

Out of the fifteen participants interviewed for the study, none could recall having completed a trauma screen at RWH. While the majority supported trauma screening in principle, most of them thought is should only be done if done properly. This meant something different to each participant.

For instance, four participants thought a trauma screen should only be done if it was done in a sensitive manner and clear reasons for why it was being done were given; two thought it should only be done if there is an internal hospital policy for responding to sensitive disclosures; two thought it should only be done it was made clear that the screen was optional and one thought it should only be done if it was done in a meaningful way and not just as a "tick box" exercise.

Of the four who did not think a trauma screen should be done, two did not think it should be done because it was too invasive or potentially re-traumatising, one thought better training of clinicians to reduce the need for a trauma screen was a better option, because they did not believe health practitioners (HPs) have the skills to know how to respond to disclosures, and one had no faith the information would make a difference to their care because they had told multiple people about their past trauma history and what types of practices might trigger them but telling people did not make a positive difference to their care. This was the case made by Suzanne, 39:

> No, I'm saying it has to have a purpose first. And if you don't have a purpose that actually centres the patient for doing that, do not do it. Because all you are doing is gratuitously collecting their trauma for no other reason that you say it's going to do something, but then you don't. Like as I said, I disclosed to every single one of the doctors that treated me at Royal Women's and none of them, I don't think that they even wrote it down. So, in that respect, don't trauma screen people because there's a complete gap between trauma screening them and actually doing anything about it. So no, at this point I think it would be honestly…. bordering on reckless. **Suzanne, 39**

One participant believed that increased support for nursing would be more useful than a trauma screen and suggested that nurses need to be trained to be able to identify trauma cues. She also believed that the information gathered needs to be properly communicated across the team to be of any use. While another participant thought that training in TIC would be of more value than screening for trauma.

The key point about trauma screening made by most participants was that it needs to be a meaningful process that is used and incorporated into the practice of clinicians, otherwise it is of no point. In fact, if patients share sensitive information but this does not result in more sensitive care, they are at risk of further re-traumatisation.

These findings are similar to those findings made by Read et al. (2007) and Snyder (2016) who assert that when the clinician gives clear reasons for asking questions and offers to link them into appropriate support services, patients only experience short term discomfort. Furthermore, McGregor et al. (2010) and Elliott et al. (2005) highlighted the importance of training practitioners to be better able to respond to disclosures of trauma, and the importance of ensuring patients know that the trauma screen is optional, not compulsory.

Chapter Summary

In summary, this chapter highlighted five key themes and demonstrated how these themes link to existing evidence on TIC. The first theme highlighted the prevalence of distressing, demeaning, or invalidating health care experiences in hospital settings, particularly for participants with an endometriosis diagnosis. The second theme showed how past distressing experiences influenced the expectations and behaviours of the participants in both negative and positive ways. The third theme outlined factors which helped mitigate or exacerbate the risk of re-traumatisation. These factors included the health care environment, the quality of communication, consistency and integration of care, and the quality of the relationships with clinicians, particularly nursing staff but also doctors and social workers.

The fourth theme emphasised the ways that the participants proactively worked to reduce the risk of re-traumatisation such as by bringing a support person with them, by developing skills and expertise that helped them better manage their health care and by engaging in self and community advocacy. The final theme found that none of the participants could recall completing a trauma screen, and while most of them thought screening for trauma was a good thing, they only thought it should be done if done sensitively and voluntarily, and only if it is incorporated into health care systems and practice. All these themes support and expand our knowledge and understanding of TIC and illustrate how important TIC is in reducing the impact of traumatising health care incidents.

Chapter 5: Discussion

This study set out to examine the health care experiences of gynaecology patients with a history of trauma, to see what aspects of their care went well, what did not go well and what factors contribute to their overall care experience. The underlying assumption made by the researcher was that patients with a history of trauma are more likely to have re-traumatising experiences in hospitals, and that care which is trauma-informed and emphasises safety, trustworthiness, choice, collaboration and empowerment, improves their care experience, reduces their risk of re-traumatisation and mitigates the impact when distressing incidents occur.

Unsurprisingly, the study findings endorse the view that TIC helps improve the care of patients with a history of trauma, and that distressing incidents occur when care is not trauma-informed. Moreover, when distressing incidents occur, TIC helps mitigate the impact of these incidents. There are many factors which contribute to patients’ care experience and either exacerbate or mitigate risk. In particular, the environment, the quality of communication and integration of systems and the quality of the care relationship play central roles in the patient care experience. For instance, while communication and systems breakdowns increase the risk of distressing incidents occurring, having support, the quality of the care relationship and patients’ own learnt skills and expertise help reduce the risk of distressing incidents occurring and mitigate their impact when they do occur.

However, there were many findings which were unanticipated, and worth further investigation. To start with, most participants had had distressing incidents either at RWH or other hospitals. Furthermore, all participants with endometriosis diagnoses had had distressing experiences either at RWH or elsewhere. Moreover, this study was of particular interest to individuals with endometriosis, and while most participants with endometriosis came into hospital with low expectations, many of them were surprised to have good experiences in hospital and wanted to champion this experience. Finally, while it was not surprising that none of the participants had been screened for trauma, their views and perceptions about the value and benefits of trauma screening were very mixed.

In the following chapter the researcher explores both the anticipated and unexpected findings in more detail, to see how they contribute to our knowledge and understanding of the care needs of gynaecology patients with a history of trauma. Moreover, by examining these unexpected findings within the broader socio-political context, the researcher explores some possible explanations for these findings. Finally, the research discusses some of the practice and research implications and study limitations.

5.1 Trauma-Informed Care Improves Care

It was not surprising to discover that those aspects of care most valued by the participants, are in line with trauma-informed principles (Fallot & Harris, 2009). Participants valued it when they knew what to expect and were kept up to date with who was caring for them and what has happening in relation to their care. Letting participants know what to expect builds trust and respect and a sense of control and empowerment which is in line with the TIC practice principles of trustworthiness and empowerment (Fallot & Harris, 2009).

Participants also distinguished clinicians who were just doing their job to those who appeared authentic and genuine. They appreciated it when they were treated like an individual and not just a number. This helped them feel seen and heard and gave them back a sense of safety, a practice principle highlighted as critical in the literature on TIC (Fallot & Harris, 2009).

Moreover, when incidents did occur, the therapeutic value of the relationship with staff helped mitigate the potentially traumatising impact of these incidents. They also valued it when clinicians allowed them to be active participants in their care, when their health concerns were taken seriously and when their expertise and efforts to manage their own health were validated. This highlights the importance of consumer empowerment as a practice principle (Fallot & Harris, 2009).

Conversely, when the care was not trauma-informed, potentially traumatising incidents often occurred. These were incidents where participants felt overwhelmed, experienced extreme powerlessness and loss of control.

Herman (2015), defines traumatic situations as those which cause feelings of "extreme sense of powerlessness and loss of control", and views those situations where individuals experience a significant loss of agency and heightened vulnerability as ones which increased the risk of re-traumatisation (Herman, 2015, p. 33). This is why TIC places such emphasis on safety, trustworthiness, choice, collaboration, and empowerment as principles central to helping individuals re-build a sense of agency and control (Fallot & Harris, 2009).

Literature on trauma highlights the need that individuals have for a sense of control, and the risk of potential re-traumatisation increases when control is compromised (Herman, 2015). For instance, for one patient, who was a victim-survivor of sexual assault, "being out of it on meds" was particularly distressing, as she was in a heightened state of vulnerability. For another participant, not knowing what to expect, and "being bombarded with people", where she was confronted with multiple unknown care professionals who were not introduced to her during her care journey was overwhelming.

Pain was a central theme for many of the study participants, as well as the impact of pain on their psychological wellbeing. So, when participants were faced with situations where they felt their pain concerns were being dismissed by clinicians, they experienced significant distress. The particular importance of acknowledgement and validation and the impact that dismissive care, particularly around pain concerns, has to individuals with a history of trauma is also highlighted in the literature (Price et al., 2006; Ross et al., 2023). Furthermore, for victim-survivors of sexual abuse, being in pain can be traumatic in its own right, and many participants felt a sense of powerlessness and loss of control when they were in pain (Panisch & Tam, 2020). For instance, one participant, who had a significant history of childhood trauma and sexual assault, felt safer and found it easier to cope with pain when she was in a private room.

Moreover, some participants felt a sense of powerlessness and loss of control when they were completely dependent on others. For instance, one participant was distressed when she was told that she would be "bedbound" and unable to mobilise after recovering from surgery. She felt that she would have coped a lot better had she been better prepared for this to happen, as this would have helped her feel more empowered. The impact that a loss of control and powerlessness can have on individuals with a history of trauma is in line with TIC literature (Raja et al., 2015; Reeves, 2015).

TIC aims to educate clinicians on what trauma is and build awareness of the types of practices which might cause distress to individuals who have a history of trauma. Many people who have experienced childhood or adult trauma have been subjected to psychological and emotional abuse and faced situations where they are made to feel that the abuse is their fault or made to feel that they are crazy, and the abuse is all in their head. Many of the participants talked about incidents where clinicians were dismissive of their health concerns or attributed psychological reasons for their pain. This finding supports the literature which highlights the importance of clinician training and education in understanding trauma (Fallot & Harris, 2009).

Furthermore, TIC emphasises the importance of staff being trained to identify the signs of trauma or re-traumatisation (Fallot & Harris, 2009). According to the literature, individuals who have experienced trauma are at risk of going into states of fight, flight or freeze when triggered (Roschild, 2000). There were many incidents that showed a lack of understanding or awareness of the signs and symptoms of trauma. For instance, one participant talked about having a panic attack, and due to her panicked presentation, she was removed from hospital by security. Another participant talked about going very quiet when triggered, which he thought could easily be mistaken by staff for compliance. Both these incidents highlight the importance of staff training and education in trauma and its signs and symptoms.

5.2 The Study was of Particular Interest to Individuals With Endometriosis

It was surprising to learn that most participants who elected to participate in the research had endometriosis, despite the project being open to all gynaecology patients. Although the population sample was very small, it was worth finding out if there were any particular reasons for the overrepresentation of patients with endometriosis and see why studies such as this one was of particular interest to these individuals.

It was beyond the scope of the study to do more than just a brief examination of the literature; however, the literature that was reviewed showed that individuals with endometriosis are more likely to have a history of trauma (Liebermann et al., 2018). This might partially explain the overrepresentation of endometriosis patients in the study.

RWH inpatient data for 2022 was also examined to see if the proportion of participants who elected to participate in the study was proportionate to the number of patients admitted into hospital during that timeframe. It was difficult to confirm data specific to patients being admitted to hospital for the emergency treatment of endometriosis; however, out of the total of 1781 planned admissions for the surgical treatment of gynaecological conditions, only 566 were for treatment of pain conditions such as endometriosis. In other words, planned surgeries for treatment of endometriosis and other pain conditions only made up a third of all planned surgeries while participants with endometriosis who elected to participate in this research made up two thirds of all participants.

Promotional material was sent to the Epworth Freemason's Endometriosis Support Group as part of the recruitment process. This might help explain the reason why such a high number of individuals who elected to participate in the study had endometriosis. However, because participants were not asked about how they found out about the study, it was not possible to find out how many participants were recruited to the study through this Group.

Nevertheless, it was still worth examining the recent rise in media and political interest in endometriosis to see if this increased interest is linked to the higher rate of interest in the study of individuals with endometriosis. This is discussed further in the next section.

Another small, but important finding of note is the fact that two participants identified as trans men. While they both had very different care experiences at their most recent hospital admission, they both had experienced distressing health care experiences in the past, and one of them also commented on how medical trauma experienced by their community impacted on their expectations and experience.

However, it was promising to see that both of the trans participants felt there had been moves towards better inclusive practice within health care settings. Because there were many differences in the care experiences of these two participants, it would be good if future studies focused on gender diverse populations to see if their experiences are replicated in the broader community.

5.3 Participants With Endometriosis Have Distressing Care Experiences

Surprisingly, most participants had experienced distressing health care, such as demeaning, invalidating or dismissive care, either recently or in the past. Moreover, all participants diagnosed with endometriosis disclosed having distressing health care experiences in past or recent hospital admissions. The researcher appraised current socio-political discourses relating to endometriosis to better understand why so many participants with endometriosis have distressing health care experiences.

Endometriosis has received a lot of media coverage over the last few years. High profile women including Gabrielle Jackson, a journalist for the Guardian newspaper and author of *Pain and Prejudice*, have helped increase awareness and knowledge of endometriosis (Jackson, 2019). Furthermore, this increased awareness of endometriosis has resulted in recent changes to research and policy. In the last twelve months in the state of Victoria, there has been a move towards addressing the gap in women's health, with significant funding of Women’s Health Hubs to treat conditions such as endometriosis being planned for the next few years[9].

According to authors such as Jackson (2019), there has been a long-term lack of awareness of and funding for endometriosis, which has negatively impacted on and contributed to the suffering of individuals with an endometriosis diagnosis (Jackson, 2019, p. 14). Jackson asserts that women experience more chronic pain than men and almost all the major chronic pain conditions affect more women than men (Jackson, 2019, p. 9). Moreover, there is a significant lack of research into women’s health, which she believes is one of the main reasons for the lack of knowledge and treatment of many of these chronic pain conditions (Jackson, 2019, p. 10).

This lack of knowledge and awareness of endometriosis could help explain why so many of the participants found it difficult to access appropriate care for their condition and reported having so many demeaning or dismissive care experiences within health care settings. Moreover, past research and funding inequities coupled with the recent, emerging public and political interest in endometriosis could also explain why many of the research participants with an endometriosis diagnosis had such strong personal and political views about it.

5.4 The Care of Clinicians Helps Reduce Distress

Not surprisingly, most of those participants who experienced distressing health care incidents during their recent hospital admission reported feeling that their care experience would have been a lot worse had it not been for the care of many clinicians (particularly the nursing staff, but also doctors and social workers). The therapeutic value of someone acknowledging and validating them, looking out for, and noticing

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[9] Investing in women's health | Victorian Budget 23/24 | Victorian Budget

them and showing them genuine care rather than just doing their own job appeared to make these potentially traumatising incidents much less distressing. It was this care relationship which enabled them to feel safe, despite these negative experiences, and being cared for by women and having clinicians show genuine care contributed to their sense of safety.

Although the importance of the care relationship in reducing distress is not in itself a surprise, it does highlight the key role that all staff, and particularly nursing, play in the implementation of trauma-informed systems. Given that the majority of nursing staff are female, and many of the participants prefer female clinicians, this finding has practice implications for the introduction of TIC into hospital settings, as well as implications for the direction of any future studies.

Moreover, social workers have a vital role in the functioning of trauma-informed systems. The gynaecology social worker already plays an important role in supporting gynaecology patients with a trauma history. They work in partnership and collaborate with them to develop plans to mitigate risk from the outset of their care journey. For example, by communicating the patients’ particular care needs to the surgical team, ward staff and others who will be involved in their care to ensure the whole care team is aware of these needs. They also support patients with a trauma history after distressing incidents occur.

The benefit of the social work role is that it works outside the various health care silos. By working across these complex and varied systems, social work is well placed to fill some of the communication gaps which contribute to distressing incidents occurring. By identifying patients at risk of re-traumatisation through use of trauma screening tools, or by working alongside other teams and participating in multidisciplinary meetings, social workers can help play a central role in mitigating the risk of systems and communication breakdowns.

5.5 Past Negative Health Care Experiences Shape Present Day Experience

While it was not surprising to find that past negative health care experiences shaped present day behaviours and expectations; it was interesting to see that though some participants avoided hospitals because of their negative perceptions, others used knowledge and expertise, developed over time, to reduce the risk of re-traumatisation.

Many of the participants had done some form of therapy or participated in peer group support, so they were able to reflect on their care experience from a place of distance. They also demonstrated a high level of health and mental health literacy, particularly participants with endometriosis, and many of them reduced the risk of re-traumatisation by bringing an advocate to support them when in hospital, or by providing information about potential trauma "triggers" to their care team.

On the other hand, many participants felt very anxious about going into hospital and often avoided going in unless they had a support person with them. One of the trans participants talked about how the medical trauma experienced by the trans community, contributed to his fear of hospitals; while the other trans participant talked about how he avoided care and brought communication tools with him into hospital, due to past distressing health care experiences.

The impact of "institutional betrayal" on particular minority groups, such as the trans community, who already experience intersecting forms of discrimination and disadvantage, highlight how critical it is to provide education and training in inclusive practices and trauma-informed care to clinicians, to reduce the risk of re-traumatisation (Smith & Freyd, 2014).

However, many of the participants with an endometriosis diagnosis came into hospital with very low expectations due to past negative health care experiences but had unexpectedly positive experiences. They used the research study as a platform to champion their positive care experience, with the hope that this would encourage clinicians to continue working in a trauma-informed way.

Given that this was an exploratory study, it is not possible to make large claims, however, it would be worth exploring in future studies, whether this finding is an anomaly, or is part of a bigger shift towards improved care for endometriosis patients. Moreover, it would be worth exploring if improved care experiences are due to better knowledge and awareness of endometriosis.

5.6 Participants With a Trauma History Proactively Reduce Risk

This study showed that patients with a trauma history already use learnt skills and expertise to reduce the risk of distressing experiences occurring. This is most likely due to them having past negative health care experiences. This finding also aligns with trauma-informed care principles which emphasise the importance of building on patients' existing skills and knowledge, listening to their individual care needs and incorporating them into trauma-informed care plans.

Many of the participants suggested ways to improve their care. For example, by better preparing patients for hospitalisation, offering peer support or social work support, checking in on them regularly to ensure they did not feel forgotten about and being clear and transparent about what to expect. This finding shows how important it is to seek the input of patients into their care. If the only change that clinicians make to practice is to seek the input of the patients, then this alone can reduce the risk of distressing incidents occurring.

5.7 Study Implications

Although this was an exploratory qualitative research study, many of the themes were supported by the literature and the findings are a valuable contribution to the growing body of evidence showing the value and importance of trauma-informed care. The study also highlighted the significance of medical trauma, particularly for patients with conditions such as endometriosis, and the particular importance of TIC for this patient group. The findings illustrate the importance of TIC as a means of reducing the risk of re-traumatisation and the therapeutic value of the care relationships in helping mitigate risk.

The findings also show how much distressing health care experiences shape the expectations and behaviour of patients, influencing their decisions whether to access care. This has health care access implications for individuals with a history of trauma. Future studies, to investigate whether patients who have experienced medical trauma are less likely to attend follow up appointments are recommended.

As mentioned earlier, social workers already play a vital role in supporting patients with a history of trauma and reducing the risk of distressing incidents occurring. Because they work outside health care silos, they are well placed to build on their existing work, in filling the gaps caused by communication and systems breakdowns.

Trauma-informed practice closely aligns with social work practice. It provides the hospital social worker with new opportunities to use the social work role to help identify patients at risk of re-traumatisation, work alongside them throughout their care journey and through advocacy, support and communication, help prevent distressing incidents from occurring.

5.8 Directions for Future Research

This study was of particular interest to individuals with endometriosis. Moreover, most of the participants with endometriosis reported having had distressing health care experiences. Nevertheless, many participants with endometriosis reported that despite having negative expectations, their recent admission at RWH was positive. It would be valuable to conduct future studies to examine if the care of patients with endometriosis is improving over time, and to see if the increased knowledge and awareness of endometriosis is resulting in improved health care experiences, particularly at RWH.

Moreover, the care experiences of patients with endometriosis were often different to those of patients with other gynaecological conditions. For instance, one participant, who was in hospital for 18 days due to issues with her gynaecological wound not healing, had very different issues to the other participants and a dominant theme in her story was the challenge of managing a long inpatient stay. It would be good to do future studies which focus on patients with other gynaecological conditions to see what differences or similarities these patients have to those with endometriosis.

This study highlighted the key role that nursing and other clinicians play in practicing in a trauma-informed way. Even when distressing incidents occurred, it was the support of staff, which helped mitigate the impact of the incident. In future studies, it would be good to examine the perceptions and experiences of clinicians, using a trauma-informed lens.

While the COVID19 pandemic impacted on promotion of the study and recruitment, there were also some positive benefits. Platforms such as Web Ex, and QR codes are now in mainstream use and have extended the possibilities of conducting research studies, particularly to regional communities. Web Ex also has the potential to level the power differential between researcher and participant, as they can participate in semi-structured interviews from the comfort of their home. This may help the participants feel more at ease. As such, the pandemic has had broader impacts on the way research is conducted which can be used in future studies.

Research participants discussed a broad range of different types of distressing experiences, however, given that this was a qualitative study it relied on research participants’ own perception of distress. As such, it was difficult to assess the psychological impact of these experiences on them. It is possible that repeated “micro” traumatic incidents might result in there being a cumulative impact of trauma. To better understand the psychological and physical impact of trauma on patients who have to come into hospital multiple times, it would be good to conduct future studies using validated tools to measure the long-term impacts of medical trauma.

As Stephanie, 28, a victim-survivor of sexual assault highlights:

> I think with things like internal ultrasounds, often the kind of mentality is, you know, “oh, you've done this so many times before that you'll be right”. When actually it's, the more you do that, the more painful it becomes, the more traumatic it can become. And yeah, I've had a lot of little jokes or remarks from doctors of, you know, “you must be used to this by now” and I am, but I'm also more traumatized every time I have.

So, I think that little remarks like that can really tear people down.

Stephanie, 28

5.9 Study Limitations

To start with, a key study finding was the fact that patients with endometriosis were overrepresented in the study sample. It was difficult to know if overrepresentation was due to the study being promoted to the Endometriosis Society, because participants were not asked the question as to how they heard about the study. Future studies should include questions about how research participants heard about the study.

Secondly, although the promotional materials were inclusive in that the study was promoted to all patients with a gynaecological condition, and not just to women, participants were not asked to volunteer their gender identity when they were asked to provide demographic information such as their age and relationship status. Two of the participants volunteered their gender as being trans, which was an important finding, given that it was such a small study. It would be good, in further studies, to proactively use inclusive language to encourage more gender diverse patients to participate in the study and learn more about the health care experiences of this small but important patient group. Furthermore, in future studies it would be good to ask participants what gender they identify with.

Thirdly, despite the study initially being promoted through the Aboriginal Liaison Worker, targeted recruitment was limited. Given what we know about the impact of intergenerational trauma on First Nations patients, in the future, more targeted recruitment would be beneficial. Moreover, due to this being a small study, it was not possible to use interpreters, due to the cost. Better resourced studies of culturally and linguistically diverse communities, in particular those communities with large asylum seeker and refugee populations would be beneficial.

The lack of representation of First Nations and gender diverse people was an issue identified in some of the United States’ Substance Abuse and Mental Health Services SAMSHA guidelines for introducing trauma-informed care into organisations. The SAMSHA guidelines drew from and expanded on Fallot & Harris’ (2009) TIC principles by recommending the inclusion of a 6th principle. This principle highlights the need for organisations to work in ways that take into account race, ethnicity and gender identity and are sensitive to the cultural or gender diverse needs of individuals (Health & Services, 2014). This researcher recommends that future studies draw from this expanded set of TIC practice principles.

Fourthly, this study was conducted in 2022, during the COVID19 pandemic. The pandemic impacted on the way that the study could be promoted, as one of the promotional strategies, placing posters in private spaces such as bathrooms and face-to-face promotion of the study, was not possible, especially in the early days of the study for infection control reasons. This is one of the many possible ways that the COVID19 pandemic restricted recruitment of participants.

Finally, because this was a Masters of Advanced Social Work research study, the study was small and only fifteen participants were interviewed. In future studies, it would be good to extend the recruitment period and increase the size of the study sample to 20 or 25 participants to see if the same themes continue to emerge. This would enable the findings to be more transferable to other contexts.

Chapter Summary

This chapter highlighted the importance of TIC. It illustrated, through use of examples, the ways in which TIC helped improve the care of patients with a history of trauma and how distressing incidents occurred when care was not trauma-informed.

It examined some of the possible reasons why the study was of particular interest to individuals with endometriosis and how years of inadequate research and funding has impacted negatively on their health care experience, contributing to them having strong political views about their care.

This chapter also discussed the role that clinicians, including nursing and social workers, have in mitigating risk and improving the care of patients with a trauma history. Moreover, it showed that past distressing health care influences the health care expectations and behaviours in both positive and negative ways. Patients may be scared and avoid care, which has implications for health care access. However, they may also build skills and expertise to better manage their health care experience. As such, the importance of listening to their needs and concerns, an important aspect of trauma-informed practice, is vital to improving their care experience.

Chapter Six: Conclusion

This qualitative research study examined the health care experiences of fifteen gynaecology patients with a history of trauma, using a trauma-informed lens for analysis. The study was carried out in 2022 at RWH, Melbourne, Victoria, Australia. Data was collected using semi-structured interviews and analysed using Braun and Clarke's Reflexive Thematic Analysis (Braun & Clarke, 2019).

The purpose of the study was to explore the health care experiences of this patient group, to find out what aspects of their care went well, what did not go well and what could be done differently. It was conducted in response to the researcher noticing that patients with a history of trauma often have distressing health care experiences whilst in hospital. The researcher wanted to find ways to improve their health care and reduce the likelihood of distressing experiences occurring and find out if trauma-informed care (TIC) improves their care experience.

There were several significant findings which are worthy of further study. To start with, most participants who selected to be part of the study had experienced recent or past distressing experiences whilst in hospital which shaped their expectations and behaviours when they attended hospital. Moreover, most participants who had distressing experiences also had an endometriosis diagnosis.

There were many mediating factors which influenced the participants' care experience and either exacerbated or mitigated the risk of re-traumatisation. These included: the quality and genuineness of the care relationship, the quality and integration of communication systems, the health care environment, and having support. Participants highly valued authentic and transparent care. They wanted acknowledged agency in their care and wanted their clinicians to check in on them and ask for their consent continuously throughout their care journey. Furthermore, most participants did not think hospitals should undertake a trauma screen unless it is done properly and took active steps to help prevent traumatising events from occurring within their hospital admissions through use of learnt coping skills and expertise.

While this is a small research sample, the study shows that gynaecology patients with a history of trauma, particularly those with endometriosis, are at very high risk of having distressing health care experiences when in hospital. The findings also show that those aspects of care which mitigate the risk of re-traumatisation align with trauma-informed principles and build on existing evidence which illustrate the value of TIC. Nevertheless, while this patient group are at high risk of having distressing health care experiences, they also actively use strategies to reduce the risk of distressing experiences from occurring, using learnt skills and expertise.

Endometriosis has historically been poorly understood or researched; however, public awareness and media scrutiny of this condition have grown in recent years, resulting in recent policy and funding changes to help improve the care of this historically much maligned condition. The fact that many of the participants with endometriosis had unexpectedly good care experiences could be attributed to improved public knowledge of this condition. Further study of patients with endometriosis would help inform improvements in the care of this patient group and contribute to our growing knowledge of the impact that health care systems can have on patients with endometriosis, a chronic health condition unique to women or AFAB individuals.

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Appendix 1 Eligibility Assessment Form

Date:

Patient Code:

Thank you for your interest in participating in this research project. We need to ask you some initial questions to make sure we are targeting the research accurately and meeting our ethical responsibilities.

	Screening Questions	**Yes**	**No**
1	Were you an inpatient at RWH between the study period_________?		
2	Are you being treated for a gynaecological condition (e.g., endometriosis, pelvic organ prolapse, problems with bladder control, chronic pelvic pain)?		
3	Are you over 18?		
4	The focus of the study is on the patient experience of individuals who have experienced challenging or painful life events to see if they have different patient experiences to other individuals. *Examples of challenging or painful life events include being a survivor or witness to family violence, witnessing or surviving a natural disaster such as a bush fire, witnessing or surviving a violent crime, witnessing or being a survivor of war or torture, being a survivor of child abuse including physical, emotional, or sexual abuse, having a diagnosis of PTSD or complex PTSD.* These are ONLY examples. We welcome participants who have experienced other painful life events. Have you experienced challenging or painful life events?		
5	Are you currently pregnant?		

6	Have you been diagnosed with cancer?		
7	Have you been diagnosed with a brain injury or a cognitive impairment which might make it difficult for you to consent to being involved in this study?		
	Office Administration Purposes Only		
	To meet the eligibility criteria, the participant must *answer yes to question 1 and 2, 3 and 4, and answer no to 5, 6 and 7. Participants who answer 'unsure' or 'maybe' will still meet the eligibility criteria; however, a note of this response will be made in the data analysis.* If the participant shows signs of distress, the interviewer must follow the **Distress Protocol – See Appendix 6.**		

Thank you for showing interest in our research. Please leave your contact details and the researcher will be in contact with you within the next few days. If any of the information or questions caused you distress, you can contact the researcher Nicola Wylie, on 03 8345 3050. Alternatively, you can access support by contacting Lifeline on 131114 or Suicide Line on 1300 651 251.

Appendix 2 Participant Information Sheet and Consent Form

Study Title: How Was Your Care? **Protocol Number: 79602**

Lead Investigator: Nicola Wylie

Associate Investigators: Dr Louise Harms, Dr Lauren Kosta, and Cecilia Judge

1 Introduction

You are invited to take part in the research project: How Was Your Care? This is because you have been a gynaecology inpatient at the Royal Women's Hospital during between February – July 2022 and have faced challenging or painful experiences during your life.

The Participant Information and Consent Form tells you about the research project. It explains what you will be asked to do if you agree to take part so that you can decide if you want to be involved. Please read this information carefully. Feel free to ask questions about anything that you don't understand or want to know more about. You can talk to a relative, friend or local doctor if you want, before you agree to participate. Participation is voluntary. If you don't wish to take part, you don't have to. You will still receive the best possible care even if you don't want to participate.

If you decide you want to take part in the research, you will be asked to sign an Information Consent Form, or we will audio record you giving verbal consent at the beginning of the research interview.

By providing us with your signed or audio-recorded consent, you are telling us that you:

- Understand what you have read
- Consent to take part in the research project
- Consent to being interviewed
- Consent to us using your personal and health information.

Let us know if you want a hard copy of the Participant Information and Consent Form

2 What is the purpose of this research?

The purpose of the research is to ask you about your hospital experience, what went well and what didn’t go well, and what we can do to improve your future care. This research will help us, and others think about the way we provide care.

Some health care practices help reduce the risk of people having distressing or ‘retraumatising’ experiences while they are in hospital. These practices focus on building trust with patients, helping patients feel safe, have more choice and be more involved in decision making relating to their care.

There is some evidence that these care principles reduce the risk of patient distress, however, there is a gap in the research. The purpose of this research is to help fill this gap, so that we can learn more about what we can do to improve the care of gynaecological patients.

This research has been initiated by one of the researchers, Nicola Wylie, Gynaecology and Oncology Social Worker at the Royal Women's Hospital. The results of this research will be used by Nicola Wylie to obtain a Master of Advanced Social Work by Research.

3 What does participation in this research involve?

If you agree to participate, you will be interviewed. The interview will take approximately 45 minutes and will be done by Web Ex (a digital platform like telehealth) or face-to-face at a time that suits you. If you are unable to conduct the interview by Web Ex or face-to-face, a telephone interview will be considered as a last resort. You will be interviewed by one of the two interviewers who are social workers at the Royal Women's Hospital. You will NOT be interviewed by anyone who has been involved in your care.

You will be given a unique identifying number, so that you can remain anonymous. The Interview will be audio recorded so that we remember what you said correctly. The recording will be transcribed and information like names of people or specific places will be removed from the transcript. The audio recording will be transcribed by a professional transcription service with a privacy and confidentiality agreement in place. We may also use quotes from the transcript of what you said to help us explain the findings to other people. When we do this, we will not include your name, or we will give you a pseudonym.

We can provide you with information about the findings from the research and have these explained by the researchers, should you request this. It is anticipated that preliminary findings from the research will be available early 2023. This research project has been designed to make sure the researchers look at the results in a fair and appropriate way and avoids research investigators and participants jumping to conclusions.

There are no costs associated with participating in this research project, nor will you be paid. However, we can reimburse you for any reasonable travel or parking costs associated with the research project visit.

4 Significance of Research

The RWH Strategic Plan views patient experience as a priority. The purpose of this research is to learn more about the health care experience of individuals who have experienced past challenging life events and identify what can be done to improve their health care.

5 Do I have to take part in this research project?

You only need to participate if you want to. If you do not wish to take part, you do not have to. You can withdraw your consent at any stage. If you do decide to take part, you will be asked to read and sign this Participant Information and Consent Form and you will be given a copy to keep. If you decide to participate or withdraw your consent, you care will not be affected in any way.

6 What are the possible benefits of taking part?

We cannot guarantee or promise that you will receive any benefits from this research; however, the aim of the research is to improve our care. We want to find out if there are any practices or processes which improve your care and reduce the chance of you experiencing distress.

7 What are the possible risks and disadvantages of taking part?

We don’t anticipate the research causing distress. However, if any of the questions upset you, you can ask for a break. If you don’t want to answer a question, we can skip it and go to the next question, or we can stop the interview immediately. If you become upset, we will offer you support from one of our qualified social workers, refer you to community services for support or give you the contact details of Lifeline or Suicide Line.

8 What if I withdraw from this research project?

You can withdraw your consent to participate at any time. If you decide to withdraw, please contact the Lead Researcher, Nicola Wylie on 03 8345 3050. If you want to withdraw, you will be asked to sign a ‘Withdrawal of Consent’ form; this will be provided to you by the research team. If you decide to leave the research project, the researchers will not collect additional personal information from you, although personal information already collected will be kept, making sure the results of the research project can be measured properly and to comply with law. You should be aware that data collected up to the time you withdraw will still be used. If you do not want your data to be included, you must tell the researchers when you withdraw from the research project, but we can't guarantee this.

9 Could this research project be stopped unexpectedly?

This research project may be stopped unexpectedly for a variety of reasons. These may include reasons such as a COVID related lockdown.

10 What happens when the research project ends?

The research findings will be promoted within the Royal Women's Hospital. A summary of key findings will be sent to be made available when the study ends. If you want a summary to be sent to you, please let the Interviewer know. Depending on what the research findings tell us, they may also be used to advocate for changes to how we care for you. The findings may be used in the researcher's thesis, in research publications and conferences. The audio recordings will be deleted once they have been transcribed. All data, including the transcribed data, will be deleted, or destroyed five years after research publication.

Part 2 How is the research project being conducted?

11 What will happen to information about me?

By signing the consent form, you are agreeing to the research team collecting and using personal information about you for the research project. Any information about you that can identify you will remain confidential and will be stored securely. Your information will only be used for the purpose of this research, and it will only be disclosed with your permission, except as required by law. In any publication, information will be provided in a way that you cannot be identified. Your medical records will not be accessed for the purposes of the research study, and you will be given a unique identifier so that your information remains confidential. If we want to use your data for any additional purpose, we will let you know and get specific consent from you to do this.

12 Complaints and compensation

If you have any complaints about any aspect of the project, the way it is being conducted or any questions about your rights as a research participant, then you may contact:

The University of Melbourne: Dr Louise Harms – Telephone 8344 9413
The Royal Women’s Hospital Consumer Advocate: Telephone 8345 2290.

13 Who has reviewed the research project?

All research in Australia involving humans is reviewed by an independent group of people called a Human Research Ethics Committee (HREC). The ethical aspects of this research project have been approved by the HREC of University of Melbourne and the Royal Women’s Hospital. This project will be carried out according to the National Statement on Ethical Conduct in Human Research (2018). This statement has been developed to protect the interests of people who agree to participate in human research studies.

14 Further information and who to contact

The person you may need to contact will depend on the nature of your query.

If you want any further information concerning this project or if you have any problems which may be related to your involvement in the project, you can contact the Lead Researcher based at the Royal Women’s Hospital: Nicola Wylie on 8345 3050 or the Associate Researcher, Dr Louise Harms, at the University of Melbourne on 8344 9413.

Reviewing HREC name Royal Women’s Human Resource Ethics Committee HREC Executive Officer Arthur Hui Telephone 03 8345 3720 Email Arthur.hui@thewomens.org.au

Consent Form

Title	*Examining the health care experience*
Short Title	*How Was Your Care?*
Protocol Number	*79602*
Project Sponsor	*Not applicable*
Coordinating Principal	*Nicola Wylie*
Associate Investigator(s)	*Dr Louise Harms, Dr Lauren Kosta,*
Location	*Royal Women's Hospital*

Name of Researcher† (please print):

____

Signature Date:

____

† An appropriately qualified member of the research team must provide the explanation of, and information concerning, the research project. Note: All parties signing the consent section must date their own signature.

Declaration by Participant:

I have read the Participant Information Sheet, or someone has read it to me in a language that I understand. I understand the research purpose, procedure, and risk. I have had an opportunity to ask questions and I am satisfied with the answers I have received. I freely agree to participate in the research and understand that I am free to withdraw at any time during the project without affecting my future care. I can ask for a hardcopy of the Participant Information Sheet or Consent Form

Name of Participant (please print):

____

Signature:

____

Signature Date:

____

For participants unable to read the information and consent form

Witness* to the informed consent process Name (please print):

____

Signature:

____

Signature Date:

____

* Witness is not to the Investigator, a member of the study team or their delegate. Witness must be 18 years or older.

Declaration by Researcher†

I have given a verbal explanation of the research project; its procedures and risks and I believe that the participant has understood that explanation.

Name of Researcher† (please print):

____

Signature:

____

Signature Date †

____

An appropriately qualified member of the research team must provide the explanation of, and information concerning, the research project. Note: All parties signing the consent section must date their own signature.

Form for Withdrawal of Participation - *Adult providing own consent*

Title	*Examining the Health Care Experience*
Short Title	*How Was Your Care?*
Protocol Number	*79602*
Project Sponsor	*Not applicable*
Coordinating Principal	*Nicola Wylie*
Associate Investigator(s)	*Dr Louise Harms, Dr Lauren Kosta,*
Location	*Royal Women's Hospital*

Declaration by Participant

I wish to withdraw from participation in the above research project and understand that such withdrawal will not affect my routine care, or my relationships with the researchers or the Royal Women's Hospital

Name of Participant (please print):

____

Signature:

____

Signature Date:

____

If the participant's decision to withdraw is communicated verbally, the Senior Researcher must provide a description of the circumstances below.

Declaration by Researcher†

I have given a verbal explanation of the implications of withdrawal from the research project, and I believe that the participant has understood that explanation.

Name of Researcher (please print):

____

Signature:

____

Signature Date:

____

† An appropriately qualified member of the research team must provide information concerning withdrawal from the research project. Note: All parties signing the consent section must date their own signature.

Appendix 3 Interview Schedule

The purpose of this research is to examine the inpatient experiences of The Women's Hospital gynaecology patients who have a history of trauma. Some of the questions are very sensitive. You can stop the interview or have a break at any time. If any of the questions cause you distress, please let the interviewer know and we can provide you with follow up support from one of our qualified social workers.

- To start with, have you read the Participant Information and Consent Form? Yes ☐ No ☐
- (*If participant answers No, the interviewer must read it to the participant prior to commencing the interview)*
- Do you have any questions about the Participant Information and Consent Form? Yes ☐ No ☐
- The interview will be recorded. Do you consent for me to start recording the interview now? Yes ☐ No ☐ (*interviewer to commence recording if answer yes).*
- Do you consent to participating in this study? Yes ☐ No ☐
- I am now going to ask you a few demographic questions.

Demographic information

Date of Interview		**Unique Identifier**		**Age**	

Do you live in Melbourne or a regional area?		**Length of hospital stay (if known)**		**Planned or emergency admission?**	
Date of hospital admission		**Relationship Status**		**Condition being treated**	

The term 'care team' includes nursing staff, doctors, administrative staff such as receptionists, and allied health staff such as physiotherapists, social workers, and pharmacists.

GENERAL

I. What aspects of your hospital health care are important to you?

II. Can you tell me in what ways your care did or didn't meet these expectations?

III. Can you describe any aspects of the care you received that seemed to make your hospital admission easier to manage? Do you mind telling me what happened?

IV. Can you describe any aspects of the care you received that made you feel distressed or upset? Do you mind telling me what happened?

Some of the aspects of care that we are interested in, particularly for patients who have had distressing or painful life experiences prior to coming into hospital are safety, trustworthiness, collaboration, choice, and empowerment. We want to ask you about your experience of safety, trustworthiness, collaboration, choice, and empowerment.

SAFETY

I. Tell me about your sense of safety while you were in hospital (both physical and psychological)? Can you tell me what made you feel this way?

TRUST

I. Did you have trust and confidence in your care team? Can you tell me a bit about why or why not? Did your care team explain what they were going to do properly, and did they do everything they said they were going to do? Did your care team maintain professional boundaries and treat you with respect?

COLLABORATION

I. Did you feel involved in decisions about your care? Tell me about what you mean.

CHOICE

I. Did you feel you had choice or control in any aspects of your care? Tell me about this.

EMPOWERMENT

I. Where there any aspects of your care where you were asked for suggestions about what could be done to improve your care while you were in hospital?

II. Tell me about any aspects of your care where you think things could have been done differently? What feedback would you give about what could be changed in the future?

SCREENING

I. *A trauma screen is a set of questions asking you whether you have experienced any adverse events in the past, such as child abuse, family violence or sexual assault. Did the hospital at any point complete a trauma screen with you?*

☐ Yes ☐ No

II. *If you answered no, can you tell me what your views are on using a trauma screen in the future? Do you think a trauma screen would have been useful for your health practitioners to have used one?*

GENERAL

I. Is there anything else you'd like clinicians to know about your health care experience?

Thank you for participating in this research study. If anything came up for you that was distressing, please let us know if you would like any follow up support.

Would you like to review the transcript of your interview to ensure it is accurate?

☐ Yes ☐ No

Would you like to be informed of any research findings?

☐ Yes ☐ No

Contact details if want to be informed of research findings or review transcript.

Distress Protocol

1. Both interviewers have the contact information for Crisis Assessment Teams, Lifeline and Suicide Line and the Associate Investigator, Professor Louise Harms.

2. Interviewers will use their skills as social workers to monitor for signs of distress during the interview and offer the participant to take breaks, skip a question or stop the interview if they would like.
3. If the participant becomes distressed and is assessed as needing immediate care during the interview process, (i.e., the participant develops acute signs of distress or suicidal ideation) the interviewer will contact emergency services or the Crisis Assessment Team.
4. If the participant is distressed but deemed not to need immediate care, the interviewer will offer the patient a follow up appointment or telephone call with a Social Worker from the Royal Women’s Hospital, who can provide emotional support and link the patient into community supports if required.
5. To minimise the risk of participant bias occurring and the risk of the participant feeling pressured to participate in the research, patients will only be asked to participate after they have discharged from hospital.
6. The Interviewer will inform the Principal Investigator as soon as is practicable of any concerns which arose during the interview process.

Lifeline – 13 11 14

Suicide Line – 1300 651 251

Safe Steps – 1800 015 188

CASA – 1800 806 292

Appendix 4 Data Analysis Process

1. The audio recorded interviews were transcribed by Triple A Transcriptions[10].
2. The transcribed interviews were then reviewed against the audio recordings for any mistakes or identifying information (such as the name of the participant or other hospitals the participant had attended) which was deleted for privacy reasons. I included basic emotions in the reviewed transcripts such as laughter, crying and long pauses.
3. Participants who had elected to review their transcripts for accuracy were sent a copy of the reviewed transcript.
4. NVIVO, a qualitative analysis database, was used to code each interview.
5. After the first three interviews were coded, the set of codes was examined and organised into basic domains. The domains were titled 'preliminary' themes. This became my initial codebook.
6. The initial codebook was shown to my supervisors for feedback. It became clear that this early codebook wasn't capturing the essence of some of the processes occurring within the interviews, so I went away to do more reading on Charmaz (2006). (Charmaz, 2006)
7. I then re-coded my data using Charmaz (2006) recommendation of conducting line-by-line coding and creating a specific type of code called a 'gerode' (Charmaz, 2006).
8. It was tempting, to reduce the sheer volume of codes, to re-use some of the commonly recurring codes within the data. However, I quickly identified that while this was appropriate some of the time, at other times it was better to

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[10] www.tripleatranscription.com.au

continue to create new codes. This ensured that codes maintained an element of context and meaning and reduced the risk of codes becoming so decontextualised that they were rendered meaningless.

9. However, the development of preliminary themes helped me to organise the astoundingly large set of codes (500 or more!) and gain some level of control over my data.
10. The preliminary themes and the codes placed into these domains became a codebook which I printed out and used as a reference guide for knowing where to place newly developed codes. I named this codebook **'Codes and Themes'.**
11. After I coded each interview, I created a summary of the interview, identifying key themes within each interview, whether the interviewee's health care experience was overall good or bad, any initial impressions about what was important or valued by each interviewee and any quotes which stood out or captured the essence of what they were trying to say.
12. Despite the amazing potential of NVIVO, I quickly realised that the visual nature of tables worked better for me. Using NVIVO to extract the information, I developed one table to count the commonly recurring codes which I named **'Recurring Themes'.** I also created a table which identified which interview these commonly recurring codes were present in and named this table '**Codes Organised into Themes and Theme Frequency'.**
13. Each table built upon the work I had done before and was part of my process for building familiarity with my data set and examining the data in a range of different ways. By examining the data according to the recurrence of commonly used codes and comparing each data extract against one another I was able to

look for overlap in themes and reduce the risk of ‘anecdotalism’ while not dismissing minor themes which might not have only been present in a few data extracts but were dominant themes in those data extracts in which they were present.

14. At this point I merged all tables into one table which I named ‘**Codes Organised into themes and theme frequency’** table. This table became my main source of data analysis. I’ve included an excerpt of this table below. (The column titled ‘theme’ was where I made notes which distilled the codes into their key unifying concepts.)
15. After I finished coding the whole data set, I re-examined the data again by going through each interview again, comparing it with the other interviews to look for patterns within the whole data set. I re-coded the whole data set to see if any new codes, identified in interviews which I had coded later in the process to see if they were also present in those interviews coded earlier in the process. I also compared interviews to one another and with the data set as a whole. This helped me refamiliarize myself with the data set as a whole and identify any new themes which I’d missed in my initial coding. I made small, but important discoveries such as the fact that half of the participants had had therapy to better manage their mental health which they felt helped them better manage potential retraumatising events from occurring and also the fact that half of the participants showed prior knowledge of what trauma-informed care is during the interviews.
16. I added the re-coded data in a different colour, to my ‘**Codes Organised into Themes and Theme Frequency’** table so that it was clear that this information

was identified later. I was now able to see how frequently themes occurred, which interviews they occurred in, while maintaining the meaning and context of individual codes.

Appendix 5 Data Extract Table

Preliminary theme (domain)	**Interviews in which theme was most dominant**	**Total No. of instances theme was present**	**Codes** (and interview number which it was present in)	**Key Concepts Present**
Being cared for by health practitioners (HPs) who genuinely care	**12** **5** **7** **11`** **14** **(3)**	**125**	• **Compassionate care mitigated the impact of potentially traumatising experiences** (5)(7)(12)(14)(1)(6)(11) • **Health Practitioners going the extra mile** (5)(4)(7)(10)(11)(9)(14) • Championing the positive experience with the surgeon (4)(14) • **Being cared for by nurses who genuinely care (1)(5)(11)(7)(12)** • **Feeling taken care of helps you feel psychologically safe (2)(7)(12)(5)(11)(14)(4)** • Feeling taken care of (9)(14) • **Distinguishing routine questions from really wanting to know (5)(9)(13)(14)(2)(7)(11)(12**	• Genuine care versus just doing your job • Relational aspect of care • Genuine Care as a protective factor in reducing risk

			) *move to being treated like an individual* • Screening for Family Violence in a meaningful way (5)(12) • Viewing a caring manner as important to conducting exams (5) • **Valuing kind and compassionate care (6)(12)(15)(2)(3)(4)(7)(14)** • Feeling like she was cared for as best as hospital could considering (6) • Nurses always asking if there's anything they can do to improve care (7) • Viewing the culture of care as positive at RWH (7) • Positively distinguishing nurse practice from practice of other Health Practitioners (11) • Trusting the nursing staff at the RWH (11) • describing how the lack of bad intent mitigated the impact of the negative health experience (14)	

Appendix 6 Participant Profiles

Stephanie, 28 (interview 1)

Stephanie is single and lives in Melbourne. She discloses that she is a victim-survivor of a sexual assault and has done a lot of therapy because of this. She had a four-day emergency admission into hospital for the treatment of chronic pelvic pain and reports her admission went well. She talks about having attended RWH and other hospitals on multiple occasions due to her condition. She also talks a lot of about the impact of living with a chronic health condition and being part of the broader endometriosis community. She also talks about some of the skills and knowledge she has learnt to cope with hospitalisation.

Lindsey, 46 (interview 2)

Lindsay is in a de-facto relationship and lives in Melbourne. She had a four-day stay in hospital for planned surgery for endometriosis. She describes her experience in hospital as being good overall. She talks about having had a lot of experience of being in hospital, mainly negative, but that this was her first experience in a public hospital.

Amanda, 28 (interview 3)

Amanda is single and lives in Melbourne. She had a three-day admission in hospital for planned surgery for endometriosis. She describes her experience in hospital as being good overall, though her experience with one of the outpatient doctors prior to her admission was very negative.

Tanya, 33 (interview 4)

Tanya is in a de-facto relationship and lives in Melbourne. She discloses that she is a victim-survivor of sexual assault and has attended therapy due to this. She had an emergency overnight stay in hospital, to treat a torsion twisted fallopian tube. She describes her health care experience as being very mixed, in that while her experience in the emergency department was very negative, she felt very supported on the ward and particularly liked the fact that most clinicians were women. She reports having limited experience of being in hospital.

Priti, 36 (interview 5)

Priti is in a de-facto relationship and lives in Melbourne. She reports that she has PTSD due to having experienced both reproductive coercion and family violence. She had a four-day emergency admission in hospital, for treatment for a rupture of cyst. She describes her health care experience as mixed in that she had negative experience in the emergency department, and experienced a distressing incident whilst in hospital, however her experience on the ward was good and the support of the nurses helped mitigate the impact of the distressing experience. She reports having both negative and positive health care experiences in hospital.

Charlotte, 22 (interview 6)

Charlotte is single and from Melbourne. She had a nine-day planned admission in hospital for treatment of endometriosis, but experienced significant side effects during surgery, where her mobility was affected, resulting in a long admission. She reports that she was assaulted by another patient at another hospital. She describes her hospital admission as mixed; while she felt very supported by the whole care team despite the adverse reaction to the surgery; she reported delays in nurses responding to buzzer.

Jodie, 42 (interview 7)

Jodie is married and from regional Victoria. She had a two-day planned surgery for treatment from endometriosis and adenomyosis. She disclosed that she was a victim-survivor of sexual assault. She describes her care experience at the Women’s as being very good, though her surgery was nearly cancelled on the day due to an emergency case, which was stressful. She reports past negative health care experiences, and difficulties accessing endometriosis specialists in regional area and delays in diagnosis of her condition.

Lorraine, 60 (interview 8)

Lorraine is married and from Melbourne. She had an eighteen-day emergency admission, for the treatment of a wound that wasn’t healing. She disclosed a history of childhood trauma. She reports that her experience in hospital was mixed due to stay being so long. While there was continuity of care within the medical team, there wasn’t with nursing, and she felt judged by nursing staff for staying in hospital so long.

Taylor, 23 (interview 9)

Taylor is in a de-facto relationship and is from Melbourne. She had a one-day hospital admission for treatment of endometriosis. She describes her health care experience at the Women’s as good. She reports having experienced past distressing health care experiences at other hospitals and she talks about the challenge of living with a chronic health condition.

Meredith, 78 (interview 10)

Meredith is a widow from Melbourne. She had a three-day planned surgery, for treatment of an internal ulcer and a pelvic prolapse. She describes her health care experience at the Women’s as good overall. She describes past negative health care experiences in the past, when she had significant surgery which she doesn’t think was needed, and she feels that she lost trust in doctors at the time. She reports having spent a lot of time in hospitals when her husband was unwell.

Suzanne, 39 (interview 11)

Suzanne is single and from Melbourne. She had a two day stay in hospital for planned surgery for treatment of endometriosis and adenomyosis. She describes her care experience as mixed; while she reports that her nursing care on the ward was good, she didn't feel prepared for what to expect in the surgery, so she found some aspects of the health care journey were very overwhelming, particularly coming across so many people. She reports that she has had a lot of distressing health care experiences and medical trauma in the past.

Fatima, 31 (interview 12)

Fatima is married and from Melbourne. She had a four-day emergency admission for treatment of endometriosis and vaginal pain. She describes her care experience at the Women's as good, but she reports having experienced a lot of negative health care at other hospitals, in particular relating to women's health issues. She reports that most of her health care is through the private system, but she attended the Women's hospital as a public patient.

Archer, 31 (interview 13)

Archer is a single trans man from Melbourne. He had two one-day admissions; one planned and one emergency, for treatment of endometriosis. He reports that he has PTSD due to significant childhood trauma. He describes his health care experience at the Women's as predominantly not good, because information important to his care, relating to his trauma triggers, wasn't passed on, and doctors witnessed him being triggered but did nothing to prevent it. He felt that while the care was inclusive from a trans point of view, the rest of his care was inconsistent and there wasn't a lot of communication across the different areas of his care. He reports that he had done a lot of therapy in the past otherwise the triggering experience would have been much worse. He reports significant amount of past negative health care experiences.

Elliott, 25 (interview 14)

Elliott is a single trans man from Melbourne. He had two two-day admissions, one planned, one emergency, for treatment of endometriosis, pelvic pain, and gender dysphoria. He describes health care as overall a good care experience although he experienced a lot of side effects to treatment and there were aspects of his treatment which didn't go as planned. He reports that the care he received was very inclusive and supportive, which helped mitigate the potential impact. He reports having experienced a lot of distressing health care experiences in the past and says he also has a lot of community trauma from hearing stories of others in the trans community having experienced significant medical trauma.

Lauren, 33 (interview 15)

Lauren is in a de-facto relationship and from Melbourne. She had a one-day planned surgery for treatment of endometrial hypoplasia. She describes her hospital admission as being good, but there were mistakes which occurred afterwards in her outpatient care which resulted in her having to wait a long time for follow up, and the results she was given at her outpatient appointment were both unexpected and upsetting, and different from what she'd been led to believe when reading about her health care on the Health Hub.