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Getting the 'Comfortable' to listen: A mixed methods study of refusal of recommended maternity care.

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Abstract

Background: The right to refuse medical treatment, held by all competent adults and unaltered by pregnancy status, is a central tenet of respectful maternity care. This right is well established in case law, midwifery and obstetric ethical guidance and health policy. However, when pregnant women decline recommended care, concerns about maternal and fetal safety can lead to conflict. Clinicians may feel their own autonomy is challenged and also grapple with ethical and medico-legal concerns. Processes to guide clinicians when women decline recommended care are rare and unstudied.

Aim: This thesis set out to support women's rights in maternity care by investigating the research question: *Could a documentation and communication process support pregnant women's rights to decline recommended maternity care?*

Methods: A sequential, explanatory mixed-methods study was undertaken in a Brisbane (Australia) tertiary maternity hospital where a structured process, the Maternity Care Plan (MCP), had been established to guide communication and documentation when women declined recommended care. The first stage of the study was quantitative and mapped the scope and use of the MCP process via a retrospective cohort study of women with MCPs. Results of the quantitative stage then informed selection of participants for the qualitative phase of the study which involved thematic analysis of in-depth semi-structured interviews with women, midwives, and obstetricians. Within the qualitative phase, two layers of thematic analysis were undertaken. The first layer of thematic analysis was descriptive, and focused on participant's experiences of the MCP process, while the second layer applied a more critical and feminist lens, foregrounding the underlying values and attitudes that drove care when pregnant women declined to follow professional advice.

Findings: The retrospective cohort study included 52 women with MCPs and concluded that the MCP process enabled clinicians to provide care outside of hospital policies but was used rarely, for a narrow range of situations and with significant variation in its application. These results were then followed up in interviews with nine women, twelve midwives, and nine obstetricians.

The descriptive thematic analysis of interviews found that obstetricians felt protected and reassured by the structured documentation and communication, while other clinicians felt reassured by the perception of obstetric authorisation. This, in turn, protected women's access to maternity care. However, inconsistencies in the implementation of the MCP process, and fragmented care, diminished both the utility of the process and women's access to it. While the MCP process provided a symbol of respect for maternal autonomy, the larger forces of patriarchy and medical hegemony remained largely unchallenged.

The feminist thematic analysis then identified both supportive and punitive interactions between women and clinicians, depending on whether the woman’s birth intentions were perceived by individual clinicians to transgress norms of patienthood and motherhood.

Key conclusions and implications: Although the MCP process was only partially and indirectly successful in supporting women’s right to refuse recommended care, a refined process has the potential to be woman-centred and effective. A new process, termed the ‘Personalised Alternative Care and Treatment’ (PACT) planning process, could provide a systems-level response to situations where women decline recommended care. The policy, practice, education and research measures that would underpin the PACT planning process are described, including the incorporation of the woman’s own account into documentation, establishing flexible pathways to initiate the PACT process and adding the failsafe of a Respectful Maternity Care Advocate. Additional research is now needed to assess the acceptability and utility of the PACT process.

Declaration by author

This thesis is composed of my original work, and contains no material previously published or written by another person except where due reference has been made in the text. I have clearly stated the contribution by others to jointly-authored works that I have included in my thesis.

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Publications during candidature

Peer-reviewed papers

Jenkinson, B., Kruske, S., Stapleton, H., Beckmann, M., Reynolds, M., & Kildea, S. (2015). Maternity Care Plans: A retrospective review of a process aiming to support women who decline standard care. *Women Birth, 28*(4), 303-309. doi: 10.1016/j.wombi.2015.05.003

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Contributor	Statement of contribution
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Keywords

Maternity care, treatment refusal, consent, refusal to treat, personal autonomy, professional autonomy, mixed methods, transformative, health services research, feminism,

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List of Abbreviations used in the thesis

ACM	Australian College of Midwives
ACNM	American College of Nurse Midwives
ACOG	American College of Obstetricians and Gynecologists [sic]
AMA	Australian Medical Association
CAM	Canadian Association of Midwives
CS	Caesarean section
EBM	Evidence-based medicine
FIGO	International Federation of Gynecology and Obstetrics [sic]
HSR	Health Services Research
ICM	International Confederation of Midwives
IOL	Induction of labour
MC	Maternity Coalition
MCP	Maternity Care Plan
PACT	Personalised Alternative Care and Treatment process
PICF	Participant information and consent form
RANZCOG	Royal Australian and New Zealand College of Obstetricians and Gynaecologists
RCM	Royal College of Midwives
RCOG	Royal College of Obstetricians and Gynaecologists
RMCA	Respectful Maternity Care Advocate
SEIFA	Socio-Economic Indexes for Areas
UK	United Kingdom
USA	United States of America
VBAC	Vaginal birth after caesarean section
VBAC>2	Vaginal birth after more than two caesarean sections
VBAC2	Vaginal birth after two caesarean sections
WHO	World Health Organisation
WRA	White Ribbon Alliance

Chapter One: Introduction and Background

Introduction

The central concern of this thesis is with women’s rights to refuse recommended maternity care. This introductory chapter will map the genesis of respect for autonomy as a key ethical principle and examine the legal decisions related to refusal of medical treatment, including in pregnant women. Despite this apparent legal clarity, this chapter will also demonstrate that women’s rights to refuse recommended maternity care are far from assured. A growing perception of the fetus as separate from the woman, together with mechanistic understandings of evidence-based medicine, make it difficult for women to decline recommended maternity care. Having mapped this context, this chapter will then outline the structure of this thesis, which explores maternity care for pregnant women who decline to follow professional advice in a hospital setting.

Woman-centred care

Woman-centred care is a widely touted gold standard in maternity care, requiring care to focus on the individual woman, incorporating not just her physical needs, but also her social, emotional, psychological, spiritual and cultural well-being (Leap, 2009). Australian health policy has long emphasised woman-centredness, including in the recent National Maternity Services Plan which described a five-year vision that “maternity care will be woman-centred, reflecting the needs of each woman within a safe and sustainable quality system” (Australian Health Ministers' Conference, 2010, p. 3; see also Australian Health Ministers’ Advisory Council, 2008; National Health and Medical Research Council, 2010). Likewise, in the United Kingdom (UK), the landmark report, *Changing Childbirth,* established the pillars of choice, continuity and control as fundamental to the provision of woman-centred care (Department of Health, 1993). Woman-centredness, and particularly the emphasis on autonomy, remained strong in the UK’s more recent National Maternity Review which sought to bridge the safety versus choice divide: “Quality services (by which we mean safe, clinically effective and providing a good experience) must be personalised” (Cumberlege, 2016, p. 8). Indeed patient-centredness (an analogous term used in other areas of healthcare) is increasingly recognised as a dimension of quality (Black, 2009; Institute of Medicine (US), 2001). Although definitions vary, patient-centredness universally incorporates respect for the needs, wants, preferences and values of patients (International Alliance of Patients' Organisations, 2007).

Terminology

This thesis focusses on situations where women's needs, wants, preferences and values may lead them to decline recommended maternity care. It is equally possible and legitimate that women's needs, wants, preferences and values may lead them to request, rather than decline intervention. However, such birth intentions are unlikely to be viewed by clinicians as challenging physician authority (Cherniak & Fisher, 2008), and are reportedly more likely to attract supportive responses from care providers than declining intervention (Lothian, 2006). At least for middle class Australian women with access to private obstetric care, interventions such as CS on request are readily available. The focus of this thesis is therefore on the more contentious situation of declining recommended care. A broad range of women's choices may fall under this banner, which I will also refer to as 'declining to follow professional advice.' Australian law does not differentiate between refusing treatment and refusing care (Curnow, 2014), although this thesis mostly uses the verb decline (rather than refuse) simply because it is less adversarial.

Some ethicists and clinicians have adopted the term 'maternal-fetal conflict' to describe situations in which pregnant women decline recommended care (Scott, 2007). However, this term misrepresents the conflict as being between the woman and the fetus, concealing the role of the care provider (Oberman, 2000). It constructs the pregnant woman as a threat to her fetus, underpinning a perceived need for paternalistic clinicians to rescue the fetus (McLean, 2009). Maternal-fetal conflict is more appropriately conceptualised as being between the woman and *her care provider's judgement* about the best interests of the fetus (Digiovanni, 2010, emphasis added). While both doctors and women are fallible in their assessment of fetal interests (Dickens & Cook, 2010, p. 172; Kolder *et al.*, 1987; Savell, 2002), it is pregnant women who have "historically demonstrated their trustworthiness (not perfection, just trustworthiness) as advocates for their children," both born and unborn (Katz Rothman, 1989, p. 194). For these reasons, the term maternal-fetal conflict will not be used in this thesis (unless quoting other authors).

A further language choice worthy of discussion relates to my preference for the term 'woman', over 'mother.' Constructing pregnant women as already being mothers invokes all of the mythology associated with that role and reduces the lives of women to mothering (McLean, 2009; Murphy-Lawless, 1998) and their bodies to "maternal environments" (Savell, 2002, p. 46). For pregnant women, choices are inevitably organised within dichotomies of safe/unsafe, order/disorder, life/death and, by extension, women's mothering identities are constructed as good/bad (Bryant *et al.*, 2007). This conflation of risk-taking with bad mothering is part of a broader social willingness to restrict pregnant women's choices (Edwards & Murphy-Lawless, 2006; Smith-Oka, 2012; Sutton *et al.*, 2011), allowing them to be "beatified in words and vilified in deeds" (Minkoff & Paltrow, 2006, p. 28).

Risk and recommended care

While declining recommended care may carry a high probability of harm to a woman or her fetus, there are many other cases where the position will not be as clear cut. Indeed studies of women's birth plans have found that most intentions can be accommodated within accepted practice guidelines and are usually "reasonable" (Deering *et al.*, 2006, p. 780). Sometimes women may make evidence-based decisions that are at odds with a care provider's usual practice. For example, although routine admission continuous electronic fetal monitoring is associated with an increased risk of caesarean section (CS), without improved fetal outcomes (Alfirevic *et al.*, 2017), it remains a widely adopted policy in Australia (Royal Australian and New Zealand College of Obstetricians and Gynaecologists (RANZCOG), 2014). Women who decline this monitoring may, therefore, be making an evidence-based decision. Likewise for women who decline routine vaginal examinations in labour, which is not an evidence-based practice (see Downe *et al.*, 2013). In other areas, such as breech vaginal birth, homebirth and water birth, the evidence is contested (see Hunter, 2014; Roome *et al.*, 2015; Young & Kruske, 2012b, respectively). The timing of a woman's refusal may also vary: some may arise throughout antenatal care if women and care providers disagree over prenatal testing or 'maternal lifestyle issues' such as alcohol or tobacco use, while others may not be addressed until birth is imminent (Oberman, 2000, p. 451).

Even where women appear to choose a riskier plan, it is unlikely that they conceptualise their choice as being for a positive experience *instead* of a safe one; women expect to achieve both (Downe, 2015). Moreover, when judging women's birth choices to be 'risky,' it is also important to note that very narrow definitions of risk and safety pervade contemporary maternity care, often ignoring the social, emotional and cultural risks that may shape women's decision-making (Edwards & Murphy-Lawless, 2006; Kildea, 2006). Women and clinicians may prioritise different risks in their approaches to maternity care, which can create tension (Kornelsen & Grzybowski, 2012). Differences in risk perception between clinicians in different settings may also influence practice (Mead & Kornbrot, 2004). While clinicians may base advice on estimates of relative risk between two options, women's decisions may focus on the absolute risk of their preferred path which may remain low even in the context of elevated relative risks (Ecker & Minkoff, 2011). Perception of risk is also highly individualised and influences the degree of compliance with recommended care (Gupton *et al.*, 2001). Although the dominance of biomedical definitions of risk may enable 'risky' birth choices to be construed as immoral (Edwards & Murphy-Lawless, 2006), that "wrongness" cannot justify compulsory medical intervention, which would be "traumatic and burdensome" (Flanigan, 2016, pp. 236-237).

Disrespect and abuse in maternity care

News and social media sources, as well as not-for-profit advocacy organisations, are increasingly highlighting cases where pregnant women's rights to refuse recommended care have been undermined (Daellenbach & Edwards, 2010; Flanigan, 2016; Morris & Robinson, 2017). For example, one American woman, Rinat Drey, is currently suing the hospital where she gave birth for performing a CS, despite her competent refusal (Pieklo, 2014; Von Zeipel, 2017). Another American woman, Kimberley Turbin successfully sued an obstetrician after he cut her perineum despite her repeatedly refusing this intervention (Improving Birth, 2017; see also: Jahir, 2014). In 2012, a Scottish woman won an apology from her birth hospital after the Scottish Public Service Ombudsman found that she "did not properly consent to the treatment administered [prophylactic antibiotics] and was wrongly put under extraordinary pressure during labour" (Scottish Public Service Ombudsman, 2012, p. 8). In other cases, in Australia and internationally, the threat of withdrawing care and child protection intervention have been used to try to compel pregnant women to accept unwanted medical treatment, such as CS (Lewis, 2012; Morris & Robinson, 2017; Townsend, 2005; Waters, 2011). Cases such as these led a US advocacy organisation, ImprovingBirth.org, to use the hashtag #breakthesilence to collect and share women's stories of coercion and rights violations in maternity care (Pascucci, 2014a). Similar campaigns in South America have included a significant body of research about humanising childbirth (see Behruzi *et al.*, 2011; Behruzi *et al.*, 2014; Behruzi *et al.*, 2010) and led to "obstetric violence" being recognised in legislation (Pérez D'Gregorio, 2010, p. 201). Obstetric violence is a form of violence against women, defined as

> the appropriation of women's body and reproductive processes by health personnel, which is expressed by a dehumanising treatment, an abuse of medicalisation and pathologisation of natural processes, resulting in a loss of autonomy and ability to decide freely about their bodies and sexuality, negatively impacting their quality of life (Sadler *et al.*, 2016, p. 50).

Disrespect and abuse in maternity care are increasingly understood as human rights issues, and as such are attracting widespread attention, including in top ranking medical journal *The Lancet* (see

Freedman & Kruk, 2014). Recent reviews of disrespect and abuse in maternity care have documented “a startling range and level of disrespectful and abusive treatment, in countries both rich and poor” (Freedman, 2016, p. 2068). These violations have also been linked with women’s disengagement from maternity care (Finlayson & Downe, 2013; Kujawski *et al.*, 2015). In 2011, the White Ribbon Alliance (2011) published their charter for Respectful Maternity Care describing the universal rights of childbearing women. The right to refuse is explicit in the charter (see Figure 1), but these rights also assure women of respectful care under all circumstances, including when they decline to follow advice. The World Health Organisation (WHO) also released a statement on the *Prevention and Elimination of Disrespect and Abuse during facility-based childbirth,* calling for quality improvement programs in maternity care to focus on respectful care (WHO, 2014). These campaigns look towards a new approach to quality in maternity care, focusing not just on mortality and morbidity but also on values and dignity (Freedman & Kruk, 2014; Prochaska, 2015).

Every woman has the right to:

1. Be free from harm and ill treatment
2. Information, informed consent and refusal, and respect for choice and preference, including the right to the companionship of choice wherever possible.
3. Privacy and confidentiality.
4. Be treated with dignity and respect.
5. Equality, freedom from discrimination and equitable care.
6. Healthcare and the highest attainable level of health.
7. Liberty, autonomy, self-determination and freedom from coercion.

Figure 1: Respectful Maternity Care: The universal rights of childbearing women (Source: White Ribbon Alliance, 2011)

What is autonomy?

The requirement to obtain consent for treatment is the law’s best attempt at protecting the right to autonomy (McLean, 2009). At its simplest, autonomy is the right to decide one’s own future and to live the life one chooses (McLean, 2009). In contemporary medical ethics, autonomy has been described as “first among equals” with beneficence, non-malfeasance and justice (Gillon, 2003, p. 307). However, this has not always been the case: Historically, beneficence (the obligation to do good) was the driving principle of medical ethics. Beneficence also provided a convenient justification for paternalistic practices, especially given the expertise gaps between doctors and patients (McLean, 2009). That is, the (often shared) assumption that ‘doctor knows best’ allowed doctors to assume authority over patients, albeit usually with good intentions. Although patient’s continue to “expect and need the beneficent and compassionate concern which is said to be central to the good practice of medicine… [they] still claim the right to make decisions that are appropriate *for them*” (McLean, 2009, p. 12, emphasis in original). A growing emphasis on patient rights (Willis, 2006) together with the evolution of legal support mandating respect for patient autonomy via informed consent, has seen autonomy given primacy in contemporary bioethics (Scott, 2002).

While there is considerable agreement about the importance of the right to autonomy, there is less agreement about what it means to be autonomous. Case law around the right to refuse medical treatment (discussed further below) reflects an individualistic account of autonomy (Wade, 2014), but some feminists have criticised this approach. When reproductive choices are framed as private and individualistic, it obscures the social context in which women make decisions (Laufer-Ukeles, 2011). This social context includes the woman’s relationships “with the fetus, her doctor, midwife, partner, family, friends and society as a whole” (Thachuk, 2007, p. 42). The concept of relational autonomy offers a different perspective, acknowledging the “social and contextual constraints and pressures that may be placed on choices while simultaneously recognising that there is value in self-determination” (Laufer-Ukeles, 2011, p. 610). Most importantly, relational autonomy acknowledges the fallacy of separating the woman’s and fetus’s interests and underpins a broad, comprehensive and bias- and conflict-aware account of informed consent (Laufer-Ukeles, 2011, p. 614). The danger in a relational understanding of autonomy is that it might be “misread as an invitation to ‘relate’ directly to the fetus as a person” (Savell, 2002, p. 67), which inevitably undermines the woman’s autonomy (Burrows, 2001).

Irrespective of whether an individualistic or relational understanding of autonomy is adopted, its prominence in contemporary bioethics is not without critics. When pregnant women decline recommended care, clinicians may also feel their own autonomy is challenged. In these circumstances, the distinction between requesting and refusing treatment becomes significant. Refusing medical treatment is an example of negative autonomy, meaning the right to be left alone, to *not* do something (Brazier, 2006; Minkoff *et al.*, 2014). Affirmative autonomy, entailing a request for a particular kind of care, is more equivocal (Brazier, 2006; Minkoff, 2006).

The importance of this distinction between negative and affirmative autonomy is highlighted in situations where a woman’s decision to refuse CS gets conceptualised as a *request* for a vaginal birth. This kind of thinking has led some scholars to argue that declining recommended maternity care carries “an implicit demand for alternative medical management” (Chervenak & McCullough, 1991, p. 13), which imposes on clinicians an unacceptable obligation to practice in ways that are “patently inconsistent with the most reliable clinical judgement” (Chervenak & McCullough, 1991, p. 14). More recently medical scholars have similarly questioned: “when the evidence is clearly against a practice, to what extent should autonomy be respected?” (Dannaway & Dietz, 2014, p818). While clinicians and women alike have the right to autonomy, contemporary bioethicists argue that clinician autonomy should not be used to limit a woman’s right to *refuse* treatment (Minkoff *et al.*, 2014) since “the risk from infringement on autonomy is greater for the patient, than the professional” (Perry *et al.*, 2002, p. 13). While shared decision-making is one, widely accepted, approach to sharing power and responsibility (Sandman & Munthe, 2010), it is unclear how decisions can be shared when patients and clinicians disagree about the best way forward: “Someone has to make the final decision, and that person is the patient” (McLean, 2009, p. 33).

The legal context

The term ‘informed consent’ is commonly used in healthcare settings to describe a clinician’s obligations to inform patients about the risks and benefits of proposed treatment options. However, the term originated in US case law, and usage elsewhere appears to invoke subtly different meanings (McLean, 2009). Despite its prevalence in the Australian lexicon, it has been rejected as part of the law here since it conflates two distinct areas of law (see *Rogers v Whitaker* [1992]) . The (in)adequacy of information given to patients is related to negligence and the clinician’s duty to warn a patient of the material risks involved in the proposed treatment (*Rogers v Whitaker),* whereas consent is the mechanism which transforms what would otherwise be unlawful contact. To be valid, consent to medical treatment must be given freely by a person with decision-making capacity and cover the treatment to be performed (White *et al.*, 2010).

Given the obligation to obtain consent, patients can also withhold consent, declining medical treatment. Australian case law recognises an individual’s right to self-determination in their healthcare, and competent adults can decline medical treatment even if that treatment would save their life (see *Hunter and New England Area Health Service v A* [2009] and *Brightwater Care Group v Rossiter* [2009]). However, the particular situation of a pregnant woman declining treatment recommended for fetal benefit has very rarely been considered by Australian courts directly. It is most likely that Australian courts would follow the position taken by English courts (Curnow, 2014; White *et al.*, 2010), where the matter was largely settled by *Re MB*. The *Re MB* Court accepted that a competent woman with capacity may decline medical intervention even though the “consequence may be the death or serious handicap of the child” (para 30) and found that a fetus does not have any separate interests capable of being taken into account by the court before birth. Similarly, in the case of *St George's Health Care NHS Trust v. S, R v. Collins and others ex parte S* (1998) the court held that:

> An unborn child, although human and protected by the law in a number of different ways, is not a separate person from its mother. Its need for medical assistance does not prevail over her rights, and she is entitled not to be forced to submit to an invasion of her body against her will, whether her own life or that of her unborn child depends on it (*St George's Health Care NHS Trust v. S, R v. Collins and others ex parte S* [1998])

These decisions rest on the legal differentiation between a fetus and a person, often referred to as the “born alive rule” (Pickles, 2013, p. 146; Savell, 2006, p. 200). That is, a fetus does not acquire the full legal status of personhood (with all the attendant rights) until it is born alive, with the moment of birth serving as a “bright line” between personhood and not (Burin, 2014, p. 494). Without the born alive rule, the fetus can be considered as a separate person whose rights can be weighed against the woman’s (Savell, 2006). Any such balancing inevitably lessens the personhood of pregnant women, eroding the rights (including to autonomy) that are accorded to all non-pregnant people (Savell, 2002).

Questioning competence

Despite the apparent clarity delivered by these decisions which uphold the born alive rule, there are numerous indications that the law continues to be willing to undermine the autonomy of pregnant women (Savell, 2002). In 2002, an Australian case (*State of Queensland v D* [2002]) saw the court authorise potential forced treatment on a pregnant woman. The case was unusual in that there wasn’t yet any indication that the woman needed treatment and she had consented to a CS, but the ruling was sought out of concern that she might withdraw her consent during labour. The woman was a prisoner and had a personality disorder. She was unaware of the proceedings and unrepresented. The decision reflected concerns about the woman’s capacity, and the court authorised future treatment in the woman’s or the fetus’s best interests if she were to withdraw consent unreasonably. The judge acknowledged the *Re MB* decision but felt that the case before him was exceptional. The outcomes of the woman’s care are unknown, including whether or not clinicians ever acted on the authority provided by the court.

In the wake of the *Re MB* court's strong affirmation of the right to refuse medical treatment, a new willingness to question the boundaries of competence has emerged (Savell, 2002). *Queensland v D* reflects that approach, as do other cases that have authorised CS on non-consenting women (Savell, 2002). Competence is demonstrated by several elements: the person's capacity to express a choice, to understand and appreciate the significance of information relevant to the decision, and to engage in a logical process of weighing up options (White *et al.*, 2010). Competence is presumed in all adults, but the more grave the decision, the lower the threshold for questioning a person's decision-making capacity (White *et al.*, 2010). As the medicalisation of childbirth has become more widespread and normalised, the very act of refusing intervention has, at times, prompted questions about women's competence (Savell, 2002). Likewise, the pain and stress of labour have been used to negate women's competence to refuse recommended care. Questioning women's competence may seem to skirt the issue of fetal rights (discussed further below), but this is belied by the emphasis it gives to fetal risk, where the best interests of the woman seem to be served only by protecting the (medically determined) best interests of the fetus (Savell, 2002).

Legal status of the fetus

Another Australian case relating to the right to decline recommended care is the findings of a South Australian coronial inquest examining the deaths of three babies whose mothers had birthed at home with known obstetric risk factors. The South Australian Coroner (2012, p. 8) rejected the contention that an unborn infant at term has no rights in law, stating that:

> One does not have to descend into protracted legal or moral debate as to the overall legitimacy of this contention to realise that the thought processes of those who advance it as an argument in support of the existence of an unrestricted right to place an unborn child at risk of harm or death, are fundamentally flawed… It is an undeniable fact that to a significant extent the law protects the right to life of the unborn infant at term.

There have also been other indicators that there is interest, in Australia, in extending legal personhood to fetuses. An Australian Government-commissioned report recommended against changing legislation to increase recognition of harm done to fetuses in crimes committed against pregnant women (Campbell, 2010), but pressure to do so has come from numerous areas in the community including doctors' groups (Campbell, 2012), police (Queensland Police Union, 2013) and state governments (ABC Lateline, 2014).

The most progress towards recognition of fetal personhood was made in New South Wales (NSW) in 2013 when the *Crimes Amendment (Zoe's Law) Bill (No. 2)* was proposed to allow separate recognition of the death of a fetus in a crime committed against a woman. The proposed changes were the result of a campaign by Brodie Donegan whose 32-week fetus was stillborn after Donegan was hit by a car driven by a drug-affected driver. Although provision exists in legislation for judges to recognise the death of a fetus as part of the harms done to the woman, *Zoe's Law* (named for Donegan's stillborn daughter) would have allowed separate manslaughter prosecution for the death of a fetus of more than 20 weeks gestation (Donegan, 2013). Although *Zoe's law* lapsed in the NSW Parliament at the end of 2014 (and would, therefore, need to be reintroduced and debated before a vote could be taken), similar legislation known as *Sophie's law* is now being lobbied for in Queensland (Caldwell, 2017; Wahlquist, 2016).

Either law could create legal personhood for fetuses for the first time in Australia. The draft *Zoe's Law* sparked criticism from pro-choice activists concerned that it could be used to limit women's access to abortion (Henry, 2013) and amongst midwives (Anolak, 2015) and lawyers (Robert, 2013b) about the impact that it could have on women's rights to decline recommended care. Such concerns appear to be warranted since similar legislation in the United States, similarly enacted to provide justice for pregnant women injured in violent crimes and with similar exclusions to protect women from judicial scrutiny, has since been used to prosecute women whose fetuses have died (Minkoff & Paltrow, 2006).

The undesirability of court intervention

Cases from the United States America (USA) offers a strong cautionary tale against court intervention to authorise intervention on non-consenting pregnant women. Paltrow and Flavin (2013) comprehensively reviewed arrests and forced interventions on pregnant women in the USA between 1973 and 2005. They identified 413 cases in which the woman's actions were criminalised by her pregnancy. That is, were the woman not pregnant, she would not have faced judicial scrutiny. The factors used to justify state intervention (either incarcerating women or authorising intervention on them) were consistently examples of declining to follow professional advice, such as avoiding antenatal care, birthing outside of hospital, drug use or refusing CS (Paltrow & Flavin, 2013).

Beyond the erosion of women's autonomy inherent in the cases documented by Paltrow and Flavin (2013), other scholars have demonstrated that, were it to become routine, judicial intervention could *expand* hospital and clinician liability (Filkins, 1997; Kolder *et al.*, 1987). This expansion of liability could arise because routine use of court orders could create a perception that clinicians were *required* to compel pregnant women to accept recommended care (Filkins, 1997; Kolder *et al.*, 1987). Also, threatened or actual court-intervention generates confusion and pressures that may trigger medical mistakes, potentially leading to further medico-legal exposure (Adams *et al.*, 2003). Perhaps partly as a result of such considerations, medical groups and obstetric colleges have adopted positions cautioning their members against seeking court orders to authorise treatment on non-consenting women (see American College of Obstetricians and Gynecologists (ACOG), 2016; Australian Medical Association (AMA), 2013; FIGO Committee for the Study of Ethical Aspects of Human Reproduction and Women's Health, 2012).

There is also a significant body of literature analysing the flaws in court decisions that have authorised intervention on non-consenting pregnant women. Although these cases often rest on privileging medical authority (Kolder *et al.*, 1987; Savell, 2002), many of the women on whom the court authorised CS, went on to birth healthy babies vaginally before that CS could be performed, suggesting that "physicians [have a] tendency to over-predict hazards" (Dickens & Cook, 2010, p. 172; see also: Paltrow & Flavin, 2013). These cases have been disproportionately brought against marginalised women, such as those from culturally and linguistically diverse backgrounds and women of low socio-economic status. The courts have also been willing to make decisions in great haste (Paltrow & Flavin, 2013; Samuels *et al.*, 2007) and often without the woman having representation or in some cases even being aware of the proceedings (Burrows, 2001). Although many have been overturned on appeal, this is often *after* the women has endured forced treatment (Nelson, 2007). Three of these troubling characteristics (specifically, an expedited decision made without the knowledge of a marginalised woman), were also evident in the one Australian case mentioned above, *Queensland v D.*

Is it difficult to decline recommended care?

Despite court intervention being almost unheard of in Australia, obstetric colleges cautioning their members against it internationally (American College of Obstetricians and Gynecologists (ACOG), 2016; FIGO Committee for the Study of Ethical Aspects of Human Reproduction and Women's Health, 2012), and strong national health policy endorsing woman-centred care (Australian Health Ministers' Conference, 2010), declining recommended maternity care remains complex and challenging. Indeed court-ordered CS is "only the most egregious indicator in a larger underlying pattern of disrespect and abuse toward pregnant and birthing women by health care providers and medical institutions" (Diaz-Tello, 2016a, p. 57). The anecdotal reports outlined earlier in this chapter indicate pregnant women who decline recommended care may face coercive efforts to get them to comply, even without recourse to the courts.

Women's autonomy is constrained when they are excluded from decision-making, perceive that they are required to accept recommended care or receive interventions without consent. Studies in the UK (Baker, 2005; Lewin *et al.*, 2005), the United States (Declercq *et al.*, 2013; Roth *et al.*, 2014), Canada (Vedam, Stoll, Martin, *et al.*, 2017; Vedam, Stoll, Rubashkin, *et al.*, 2017), Australia (Thompson & Miller, 2014) and globally (Bohren *et al.*, 2015; Reis *et al.*, 2012) have documented such experiences and contributed to a growing awareness of disrespect and abuse in high resource settings. Even where consent is sought from women, these studies have also raised concerns about the extent to which that consent is freely given. The related notions of autonomy and informed consent are sometimes, erroneously, used interchangeably (Bryant *et al.*, 2007), assuming that if a woman has given informed consent, then she has done so autonomously. Indeed Dixon-Woods *et al.* (2006) found that women consented to surgery even when they did not want to because power disparities between them and clinicians made it difficult to resist expectations of compliance. Other authors have similarly theorised that women fear hostility and withdrawal of care, particularly late in pregnancy as the power disparities between women and clinicians widen (Cherniak & Fisher, 2008). Disadvantaged women may be particularly unwilling to seek control over their maternity care, due to the perceived risks of non-compliance and inadequate information giving by care providers (Ebert *et al.*, 2014). At the other end of the socio-economic spectrum, a study of women's experiences in private obstetric care found that although women "are not 'passive dupes' of obstetric hegemony… their autonomy is nonetheless constrained by their relationship with their obstetrician and an increasing normalisation of medical birth" (Campo, 2010, p. 1). Such findings have led some authors to conclude that "the ideal of informed consent as the outcome of rational choices exercised by autonomous agents was far from being achieved" (Dixon-Woods *et al.*, 2006, p. 2750) and indeed "remains profoundly problematic" (Daellenbach & Edwards, 2010, p. 221)

Studies of clinical practice have also borne out concern about the opportunities women have to decline recommended care. Scamell and Stewart's (2014) study of midwifery practice around vaginal examinations found that midwives sometimes conducted vaginal examinations without the knowledge or consent of the woman. Such routine practices may be "rarely presented as a choice" (Kotaska, 2007, p. 176). The illusion of choice, however, is sustained as clinicians support women to make the final decision only where the woman's intentions accord with the care provider's preference (Eri *et al.*, 2011; Stapleton *et al.*, 2002). Decisions of competent adults that are at odds with the care providers' recommendations may provoke resentment (Symon *et al.*, 2010). In practice, women are "obliged to choose what is set up as the most obvious and sensible option" (Bryant *et al.*, 2007, p. 1192; see also: Edwards & Murphy-Lawless, 2006). Giving women control over decision-making may be limited to pretence, with information-giving manipulated to support clinician preferences (Hall *et al.*, 2012).

Indeed, the rhetoric of choice in maternity care deflects attention from the "irrevocably unequal" social relationships within which supposed choices are made (Crossley, 2007, p. 559). Rather, women strike "patriarchal bargains" (Kandiyoti, 1988, p. 274), that is, they strategise within their particular constraints, enabling them to resist where and when possible (Bobel, 2007). The concept of choice is a liberal fiction that serves to disguise and justify social inequities, particularly those of gender (O'Reilly, 2007).

Medical dominance

In maternity, two concurrent patriarchal processes have facilitated medical dominance over childbirth. Firstly pregnancy and birth came to be viewed as pathological, necessitating medical supervision and intervention, and secondly, institutionalised birth became the norm (Benoit *et al.*, 2010; Murphy-Lawless, 1998). One consequence of the institutionalisation of birth was a role reversal where women (rather than birth attendants) became visitors in the birth environment, with the associated expectation of compliance with institutional policies and practices (Murphy-Lawless, 1998). Arguably, these two changes allowed medicalisation to gain more prominence in maternity than in other domains of healthcare (Benoit *et al.*, 2010).

Murphy-Lawless (1998) traces the history of obstetric dominance and argues that it was built on a belief in the incompetence and unreliability of women, whether to birth babies or as midwives. This ideology was central to the building up of the obstetric discipline, which relied on the discrediting of female midwives to bring birth from home into hospital and under medical control. It matters little that obstetrics is now practised predominantly by female doctors (Robson, 2016), albeit with female doctors under-represented in leadership roles (Bismark *et al.*, 2015). Indeed in arguing that obstetric violence is gendered, Diaz-Tello (2016a) posits that it is the gender of the victim that defines it as such, irrespective of the gender of the perpetrator. The medicalisation of pregnancy and birth can be seen as a "system of care designed for the comfort of the men who control the services, rather than for the women they serve" (Murphy-Black, 1995, p. 275). Murphy-Black's notion of "comfortable men" doesn't refer to just males or obstetricians, but to those (regardless of gender or profession) who have been enculturated into contemporary medicalised maternity care.

However, since its "golden age" in the first half of the 20th century, medical dominance has been challenged on several fronts (Willis, 2006, p. 422). Concerned with controlling the spiralling costs of healthcare, governments have sponsored the development of evidence-based guidelines to address significant and inexplicable practice variation (Willis, 2006). In maternity, such initiatives have often focused on reducing the CS rate (New South Wales Health, 2010; World Health Organisation, 2015). Simultaneously, legal standards have shifted to require doctors to defend their actions in terms of what is accepted medical practice (Willis, 2006). Government policy changes have also seen other healthcare professions increasingly authorised to do work formerly reserved for doctors. In Australian maternity care, the best example of this was the extension of Medicare funding to midwives in 2010 (Department of Human Services, 2014). Medicare, Australia's universal healthcare system, was established in 1984 and has endowed medical dominance with state support (Benoit *et al.*, 2010).

Autonomy and medical dominance

Today, obstetrics claims to have largely saved women from the threat of death in childbirth. Such claims overstate the often contradictory effects of medicalisation on maternal mortality and serve to undermine women's agency (Murphy-Lawless, 1998). Numerous authors have argued that women's and midwives' autonomies are linked (Ebert *et al.*, 2014; Kirkham *et al.*, 2002; Mander & Melender, 2009; Murphy-Lawless, 1998). Kirkham *et al.* (2002) reported that women perceived it was rare to find midwives who would support their decision to decline recommended care, but that women accepted this lack of advocacy because they perceived that midwives were relatively disempowered within hospital hierarchies. "The woman's autonomy is largely dependent on the midwife's ability to practice autonomously" (Mander & Melender, 2009, p. 638). Rigid adherence to policies, at the expense of woman-centred care, has also been found to be less common in healthcare cultures characterised by high levels of collaboration, open communication and trust (Hall *et al.*, 2012). The vastly different professional ideologies of obstetrics and midwifery may also undermine women's autonomy.

In Australia particularly, women are caught in the crossfire in what has been described as the "birth wars," a philosophical schism dividing the "mechanics" and the "organics", groups which typically divide along professional lines between obstetrics and midwifery respectively (MacColl, 2009). In part this is driven by the parallel public and private systems of health care provision, where 27% of women access private obstetric-led care and birth in private hospitals (Australian Institute of Health and Welfare (AIHW), 2015), subsidised by Government support of private health insurance. Private midwifery is rare in Australia as access to public hospitals relies on private midwives having collaborative arrangements with doctors, yet no mechanisms are in place to ensure that doctors will collaborate and most refuse (Wilkes *et al.*, 2015). Instead, most midwives are employed in public hospitals where care is fragmented, and where women may be denied access to care if they do not comply with hospital policies (discussed further below). Access to continuity of midwifery care is also limited; only 31% of hospitals offer caseload care, serving just eight percent of birthing women (Dawson *et al.*, 2016). Less than two percent of Australian women birth in birth centres and few public homebirth models operate (AIHW, 2015). Unlike the UK, there is no assurance of women's rights to choose their place of birth (Department of Health, 2007).

Woman-centred care vs evidence-based medicine

In some cases, women's choices may be constrained because certain options are "not on the table" (Charles, 2012, p. 24) as individual clinicians or entire hospitals decide that they do not offer services to certain birthing women, such as those planning vaginal births after previous CS (VBAC) or vaginal breech births (Pratt, 2013). While these policies may be developed in response to an evidence base, Kotaska (2007, p. 177) asserts that "in a climate of risk reduction at all costs, a woman's autonomy is often lost through our interpretations of the evidence and in our threat of abandonment" which is encoded in policies which make access to care conditional upon compliance. Indeed, invoking 'hospital policy' curtails dialogue with women about their options and rights to refuse (Bensing, 2000; Charlwood, 2004; Williamson, 2005).

In other areas of healthcare, harm minimisation, rather than prohibition, is more widely accepted as clinicians "make and support options that may make certain behaviours less risky, even if not risk free or recommended" (Ecker & Minkoff, 2011, p. 1182). This should be all the more true in maternity care where restrictive policies do not eliminate risk, only favour the risks, for example, of CS over the risks of vaginal birth (Pratt, 2013). Indeed, failing to offer particular services such as vaginal breech birth has led to the loss of clinician skill and resulted in maternal and fetal deaths (Kotaska, 2011b). In some settings, women must 'choose' between unwanted surgery and losing access to maternity care (Pratt, 2013), a situation which may seed "unwilling consent" to surgery, which harms women due to the loss of dignity (Laufer-Ukeles, 2011, p. 612).

There is, nonetheless, a growing emphasis on the use of evidence-based clinical guidelines to standardise practice (Daellenbach & Edwards, 2010; Kotaska, 2011a). Evidence-based medicine (EBM) is "the conscientious, explicit, and judicious use of current best evidence in making decisions about the care of individual patients" (Sackett *et al.*, 1996, p. 71). The growing prominence of EBM has been valuable in displacing practices based only on tradition and anecdote, but it has also had some negative consequences (Greenhalgh *et al.*, 2014; Klein *et al.*, 2007). Although it may appear to challenge the authority of individual expertise, EBM's appeal to the authority of evidence has actually reinforced medical dominance (Goldenberg, 2006). Efforts to reduce variation in clinical practice have yielded clinical guidelines that solidify into rules (Kirkham, 2004a) and undermine women's choices (Daellenbach & Edwards, 2010), as adherence is advocated for reducing clinicians' medico-legal risk (Chandraharan & Arulkumaran, 2006). Although contemporary understandings of EBM emphasise the importance of both clinician experience and patient preferences (Greenhalgh *et al.*, 2014), Bensing (2000, p. 17) argues that patient-centred care and evidence-based medicine "seem to belong to different worlds." Deviating from policies and guidelines to provide woman-centred care is regarded by clinicians as likely to (at least) attract censure from colleagues (Hall *et al.*, 2012; Thompson, 2013). Kotaska (2011a, p. 97) therefore calls for a "quantum leap" in both the content and application of clinical guidelines to prioritise patient autonomy.

Conclusion and thesis outline

This chapter has identified respect for autonomy as a foundational ethical principle in contemporary maternity care and linked it to the legal doctrine of consent. Within that context, however, growing willingness to separate the woman and her fetus, obstetric dominance and dogmatic approaches to evidence-based medicine, continue to undermine women's autonomy. These issues are increasingly understood as part of the global problem of disrespect and abuse in maternity care.

Having mapped this context, the following chapters report on a study undertaken to support women's rights to decline recommended maternity care by promoting the need for systems-level responses to refusal. Chapter Two reviews the literature around refusal of recommended maternity care, finding that scholarly attention has focused on the attitudes of clinicians (mainly obstetricians) to court intervention. This narrow focus has largely overlooked the study of non-coercive measures as well as the views and experiences of women who decline recommended care. Chapter Three will then describe the use of Health Services Research and matricentric feminism to guide a sequential mixed methods study attending to these gaps. Chapters Four, Five and Six each reproduce a published paper arising from this thesis and present the findings of a retrospective review, descriptive and feminist thematic analyses of interview data, respectively. Chapter Seven, the fourth published paper arising from this thesis, brings these chapters together to demonstrate the value, necessity and challenges of conducting research strategically to drive change in maternity services. Finally, in Chapter Eight, I conclude this thesis by proposing a way forward, towards respectful maternity care for women who decline to follow professional advice.

Chapter Two: Literature

Introduction

Chapter One mapped how and why respect for autonomy replaced beneficence as the driving ethical principle in healthcare and explored the legal roots of pregnant women's rights, held in common with all competent adults, to decline recommended care. Despite strong legal precedents, there is a substantial body of evidence, both scholarly and anecdotal, suggesting that declining recommended care is highly problematic for pregnant women and the clinicians that care for them. Having established that context, Chapter Two reviews the published literature on maternity care for women who decline to follow professional advice.

Search Strategy

The literature reviewed in this chapter was identified using keyword searches for MESH terms 'obstetrics, 'midwifery' or 'maternity' and 'treatment refusal,' 'refusal to treat,' 'maternal rights,' 'fetal rights,' or 'maternal-fetal conflict,' through CINAHL, MEDLINE (via EBSCO Host), Ovid, EMBASE, PUBMED (NCBI), the Cochrane Database of Systematic Reviews, and Google Scholar. Search results were limited to full-text, peer-reviewed articles written in English and published since 1995. Earlier articles were also included where they were germinal to particular debates. Studies of any methodology were included, with abstracts reviewed to confirm each paper's relevance to the focus on pregnant women who declined recommended care. Relevant papers with a focus on homebirth were also included, given that many obstetric and medical organisations maintain opposition to the practice (Roome *et al.*, 2015) such that "homebirth is but one example of a patient choice that might differ from what a provider feels is in a woman's best interests" (Ecker & Minkoff, 2011, p. 1179). Finally, a purposive search of grey literature was also conducted, to map the professional and ethical guidance available to midwives and obstetricians in Australia and other comparable jurisdictions (New Zealand, the United Kingdom [UK], the United States of America [USA] and Canada).

Delimiting the scope

Although the topic of refusal of recommended maternity care is associated with the broader reproductive rights debate, literature which focused only on abortion, assisted reproductive technologies, or surrogacy was excluded. The focus here is on pregnant women who continued their pregnancies, but whose maternity care intentions did not align with professional advice. Literature examining parent's healthcare decision making for born children was also excluded, as these are necessarily complicated by the separate rights of the child. Also, there is also extensive literature on patient adherence to prescribed treatment, both generally (see Vermeire *et al.*, 2001) and in the context pregnancy specifically (see Oladejo & Bewley, 2012). However, this was also excluded since its focus is on medications to manage medical conditions, rather than maternity care more broadly.

There is also a growing body of literature centred on the issues of disrespect and abuse in maternity care. Bowser and Hill's (2010, p. 9) landmark study identified seven evidence-based domains of disrespect and abuse: "physical abuse, non-consented care, non-confidential care, non-dignified care, discrimination based on specific patient attributes, abandonment of care, and detention in facilities." These were later extended by Bohren *et al.* (2015, p. 7) to include "poor rapport between women and providers" which was comprised of "ineffective communication", "lack of supportive care" and "loss of autonomy." While there is clear alignment between the domains of disrespect and abuse and the right to decline recommended maternity care, the research in this area has not focused on the intersection of these two issues. The majority of research on respectful maternity care has also been conducted in low-resource settings, mainly in Africa (see Asefa & Bekele, 2015; Bradley *et al.*, 2016; Kruk *et al.*, 2014; Kujawski *et al.*, 2015; McMahon *et al.*, 2014; Moyer *et al.*, 2016; Rominski *et al.*, 2016). Because disrespect and abuse are likely to manifest differently in low and high resource settings (Molina *et al.*, 2016), the literature on disrespect and abuse in maternity care is not reviewed here in detail.

Much of the literature about pregnant women who decline recommended care has been produced by what Oberman (2000, p. 452) terms a "veritable cottage industry for scholars in ethical, legal, medical, religious and philosophical circles." The status of the fetus is highly contested, and numerous papers have attempted to resolve women's and clinicians' obligations. These debates about the status of the fetus are relevant here insofar as they reflect how clinicians' views on the fetus may influence women's care. Most empirical research about pregnant women who decline recommended care has been devoted to refusal of caesarean section (CS; see Adams *et al.*, 2003; Chigbu *et al.*, 2009; Chigbu & Iloabachie, 2007; Cuttini *et al.*, 2006; Danerek *et al.*, 2011; Samuels *et al.*, 2007) and, to a lesser extent, blood products (see Iris *et al.*, 2009; van Wolfswinkel *et al.*, 2009). Studies examining other maternal refusals are rare. Similarly, these studies have focused on the attitudes of obstetricians; the attitudes of midwives and the experiences of either professional group have received less attention. Nonetheless, these studies collectively raise questions about respect for women's autonomy in maternity care. Several case reports have been published on this topic, attesting to the ethical and moral turmoil experienced by clinicians (see Avci, 2015; Biscoe & Kidson-Gerber, 2015; Brass, 2012; Curtis, 2010; Dann, 2007; Osuna *et al.*, 2015; Perry *et al.*, 2002; Weiniger *et al.*, 2006). Several studies have also described the demographics and clinical outcomes of women who have declined recommended care (see Ande *et al.*, 2010; Fiscella *et al.*, 2007; Iris *et al.*, 2009; Ribak *et al.*, 2011; Tucker Edmonds *et al.*, 2014). However, women's own voices have been given less attention in the literature on this topic.

Irrespective of their focus or participant composition, the prospect of poor perinatal outcomes and the turmoil experienced by clinicians has led to widespread calls for guidance for clinicians and a harm minimisation approach (see Chigbu & Iloabachie, 2007; Cuttini *et al.*, 2006; de Crespigny & Savulescu, 2014; Ireland *et al.*, 2011; Kotaska, 2017; Kruske *et al.*, 2013). Both within Australia and internationally, relevant codes of ethics and the positions statements of midwifery and obstetric colleges call for respect for women's autonomy, but there is little clarity over just how to provide care in the context of maternal refusal. Only four scholarly papers (Chervenak & McCullough, 1990; Deshpande & Oxford, 2012; Kotaska, 2017; Pinkerton & Finnerty, 1996) and two professional guidelines (Australian College of Midwives (ACM), 2014; Ministry of Health, 2012) have described processes to aid clinicians navigating this complex terrain, but there are no published reports on the impact of these processes in clinical practice nor on the experiences of women or clinicians using them.

Conceptualising the fetus

Ethicists have produced a substantial body of literature debating the ethical implications of pregnant women declining recommended maternity care. However, the majority of ethics articles identified in the literature search were ethical debates, rather than empirical research. Indeed empirical research is rare in bioethics (Borry *et al.*, 2005). Despite the volume of literature, most scholars reach the same conclusion: "In all but the most extreme circumstances, it is impermissible to infringe upon the pregnant woman's autonomy" (Oberman, 2000, p. 452). Renewed debate is sparked each time a new example of maternal refusal is identified, although again the consensus rejecting infringing on maternal autonomy is "near universal" (Oberman, 2000, p. 453). Ethical debates about the status of the fetus are especially relevant to this study.

Given the increasing recognition of fetal personhood, and the role this has played in undermining the autonomy rights of pregnant women (as discussed in Chapter One), ethical debate about the most appropriate conceptualisation of the fetus in contemporary maternity care settings is worth considering. That said, the moral status of the fetus will not be resolved in these pages, nor, arguably, ever. Chervenak and McCullough (1996) have sought to skirt this irreconcilable debate by proposing an alternative conceptualisation of the fetus. They argue that irrespective of the moral status a fetus may or may not have (that is, whether or not a fetus should be considered a person with the concomitant rights), it should be regarded as a patient. Patienthood requires that a human be presented to a physician for treatment that will likely yield benefit and in this way, it invokes clinicians' beneficence-based obligations. Chervenak and McCullough (1996) argue that the viable fetus is a patient and that a pre-viable fetus becomes a patient when the pregnant woman chooses to give it that status (by seeking treatment on its behalf). Chervenak *et al.* (2011) built on their conceptualisation of the fetal patient to propose the Professional Responsibility Model, and apply it to decision making about CS on maternal request, vaginal birth after CS (VBAC) and homebirth (Chervenak & McCullough, 2013; Chervenak *et al.*, 2013). Chervenak and colleagues reject the primacy of maternal autonomy, which they regard as rights-based reductionism. Instead, they call upon doctors to "justifiably limit the woman's rights by limiting the scope of clinically reasonable alternatives" (Chervenak *et al.*, 2013, p. 34).

The fetus-as-patient concept and the "Professional Responsibility Model" (Chervenak *et al.*, 2011), however, have not gone uncontested. While other scholars concede that fetal patienthood does not, in and of itself, accord rights to a fetus, they do argue that it carries problematic connotations of separateness from the pregnant woman (Lyerly *et al.*, 2008; Savell, 2002). Inevitably, this separation leads to policy development that is punitive to pregnant women (Premkumar & Gates, 2016). It reduces the woman to an 'incubator' and erodes her personhood (Lyerly *et al.*, 2008; Savell, 2002). Chervenak and McCullough argue that conceptualising the fetus as a patient invokes the clinician's duty to act beneficently and Strong (2008) concurs that this duty is universally accepted. However, Strong (2008) rejects the implication that this duty is owed *to the fetus*. Rather, Strong (2008) argues that this duty is more appropriately conceptualised as a duty to the woman to act in ways that promote her health, and a duty *to the woman* to promote the health of her fetus (my emphasis), thus avoiding the pitfalls of separating the woman and fetus in the minds of care providers. Minkoff and Paltrow (2006) echo this conclusion, finding that clinicians' obligations to the fetus extend only to the boundaries set by the woman's consent. Minkoff *et al.* (2014, p. 1100) conclude that "although there are dissenting voices who feel that superseding obligations to a fetus may appropriately attenuate a mother's right to refuse, those voices remain outside the mainstream of ethical thought." Cheyney *et al.* (2014, p. 2) go further, accusing Chervenak and colleagues of being out of step with "contemporary democratic principles of free choice and autonomy… and women’s control over their own bodies [and] demonstrating remarkable disregard for the importance of shared decision making and informed choice in maternity care.”

Another variant of the fetus-as-patient model is to argue for the rights of future or potential children (Minkoff *et al.*, 2014; Savulescu, 2007). For Savulescu (2007), the rights of the future child are sufficiently compelling to argue that pregnant women have a duty to accept recommended treatment for the benefit of their fetus. By extension, Savulescu (2007) argues that state intervention to compel such treatment is acceptable where the proposed treatment does not significantly harm the woman. The problematic nature of narrow definitions of safety were discussed in Chapter One, and Savulescu’s contention, which implies that forced treatment should be evaluated only in terms of its physical risks, similarly fails to recognise the importance of social, emotional, spiritual and cultural safety (see Edwards & Murphy-Lawless, 2006; Gyamfi *et al.*, 2003; Kildea, 2006; Kornelsen & Grzybowski, 2012).

Savulescu’s (2007) suggestion that forced medical treatment would not significantly harm a woman is also at odds with other scholarly thinking. McLean’s (2009, p. 149) analysis of European case law concluded that forced medical treatment interferes with a woman’s right to privacy and “amount[s] to inhuman and degrading treatment.” As a result, McLean (2009) concluded that forced medical treatment breaches Articles Three and Eight of the European Convention on Human Rights. Another ethicist, Scott (2007), similarly argued that a woman’s reasons for refusing medical treatment determine the degree of harm possible. More serious reasons for refusing treatment result in greater risk of harm if overridden (Scott, 2007). Other ethicists have acknowledged the rights of potential children without accepting an erosion of women’s rights. Minkoff *et al.* (2014) agree that potential children have interests before birth, but strictly limit this to affirmative autonomy (as discussed in Chapter One). Minkoff *et al.* (2014) therefore conclude such interests should be weighed by physicians considering maternal *requests* for intervention, but that they should in no way limit a woman’s right to *refuse* treatment. In other cases, ethicists have noted that even if fetuses were accorded full personhood, “in no other area of public policy does one person’s right to life entitle the state to forcibly require another to undergo a risky medical procedure that may violate her deeply held commitments” (Flanigan, 2016, p. 240).

Clinician’s conceptualisation(s) of the fetus is one topic that has been studied empirically in bioethics. Williams *et al.* (2010) conducted focus groups in two English hospitals with mixed groups of maternity care providers (*n*=70; including medical, midwifery, allied health clinicians). They found that clinician’s conceptualisations of the fetus were fluid and shifted with the woman’s perceptions of it. However, the study also concluded that staff influenced the woman's perception and it was unclear how clinicians assessed the woman's perceptions. A similar study conducted in Australia reported on how increasing use of technology such as ultrasonography has led obstetricians to regard the fetus as a separate patient (Edvardsson *et al.*, 2015). Although obstetricians held a range of views about when a fetus acquired personhood (contrary to the clarity provided by the law), they reported the ability to separate their personal views from their practice. Obstetricians', reportedly unanimous, support for maternal autonomy was, however, personally distressing when maternal or fetal well-being were at risk. Edvardsson *et al.* (2015, p. 1) call for "careful consideration" of how to protect maternal autonomy in the context of ever-expanding medical and technological opportunities to visualise, diagnose and treat the fetus and the concomitant appeal of conceptualising the fetus as a separate patient.

Attitudes and experiences of clinicians

The majority of empirical research concerning women who decline recommended maternity care focusses on refusal of CS and blood products (the latter being a phenomenon most commonly attributed to members of the Jehovah's Witness faith; see Gyamfi *et al.*, 2003), and obstetricians' attitudes to court intervention. This focus has left significant gaps in the literature. The impact of declining recommended care other than CS and blood products, such as routine antenatal care (e.g. ultrasounds) or routine intrapartum care (e.g. vaginal examinations in a normal labour), is largely undocumented in the literature. The attitudes of midwives have also received scant attention, and the interplay between the attitudes, experiences and practices of either professional group has been explored only through a limited number of case studies, and without attention to women's perspectives. The literature concerning the experiences and attitudes of women and clinicians to maternal refusal is reviewed in the following sections.

Obstetricians' attitudes

Several studies have been conducted in the USA investigating the prevalence of, and obstetricians' attitudes to, court-ordered obstetric intervention. Beginning with Kolder *et al.* (1987), and followed by Elkins *et al.* (1990), Adams *et al.* (2003) and Samuels *et al.* (2007), these studies documented broadly declining willingness amongst obstetricians, over time, to seek court orders to authorise intervention on non-consenting women. However, the highest levels of willingness to support court intervention were reported in the most recent study, where Samuels *et al.* (2007) found that 51% of respondents would support court-authorised intervention in a hypothetical scenario involving maternal refusal of CS recommended at term to prevent certain fetal death. Respondents' levels of willingness to support court authorisation varied with the woman's characteristics, decreasing if the hypothetical scenario identified the woman as a lawyer, if the refusal was based on her religious beliefs, if the woman's husband agreed with her refusal, if the fetus had Down's Syndrome or if the recommended CS was very risky for the woman herself. Adams *et al.* (2003) similarly concluded that obstetricians were most troubled by refusal of recommended care in particular situations. The most problematic situations for obstetricians were those that involved a woman at the end of her pregnancy, particularly when the refused treatment was the accepted standard of care, and was perceived by clinicians to entail little risk to the woman but deliver significant benefit to the fetus (Adams *et al.*, 2003).

Studies conducted in Europe report lower levels of willingness to override maternal autonomy than the above US studies. A 2006 study of European obstetricians (n=1530; Cuttini *et al.*, 2006) investigated their self-reported responses to a hypothetical scenario involving a competent woman's refusal of emergency CS for acute fetal distress. Of the eight surveyed countries, UK obstetricians were the only group where more than half of respondents indicated an intention to "accept the woman's decision and assist vaginal delivery" (59%; Cuttini *et al.*, 2006, p. 1121). Ongoing efforts to persuade the woman to accept CS were widely reported in the survey. Court intervention was reportedly entertained by sizable minorities of obstetricians, but only outside the UK. Intention to proceed with CS without the woman's consent was uncommon but still reported.

A similar study (Chigbu *et al.*, 2009) explored the attitudes of obstetricians in Nigeria to several hypothetical scenarios, all involving maternal refusal of recommended CS. Obstetricians expressed the opinion that ongoing counselling was their preferred way of "managing" maternal refusals, but resource constraints were likely to lead them to "insist on planned caesarean delivery" (Chigbu *et al.*, 2009, p250). Such a finding suggests that obstetricians in that study viewed counselling as a way of persuading women to accept recommended care, rather than being respectful of autonomy. Indeed where women could not be persuaded to accept CS, they were refused further care at the facility. Although the low-resource setting means the results may not be generalizable to higher resource settings, this study was the only one that considered obstetric responses to planned CS (rather than emergency).

This focus on attitudes to court intervention and the apparent willingness of obstetricians to override maternal refusal, or at least employ strong persuasive measures, has persisted long after definitive court decisions in both the UK and USA (as discussed in Chapter One). This suggests that despite these precedents and professional colleges’ cautioning against coercive measures (discussed further below), respect for maternal autonomy may still be problematic for considerable numbers of obstetricians.

Midwives’ attitudes

The attitudes of midwives have received comparatively less attention, with only two studies located that examined midwives’ attitudes to maternal autonomy. Mair and Kenny (1996, p. 9) surveyed 744 Australian midwives on their views about “fetal welfare,” within a broader focus, not restricted to CS refusal. Mair and Kenny (1996) found that 26.6% of Australian midwives supported court intervention to authorise treatment for the benefit of the fetus where the woman had refused, 43.1% supported legal sanctions for women whose actions or inactions caused harm to her fetus, and 35.9% agreed that midwives and doctors had the right to refuse to care for women who withheld consent to treatment. Although the authors concluded that “Australian midwives generally supported the right of women to self-determination” (Mair & Kenny, 1996, p. 13), substantial minorities of midwives held divergent views. More recently, Danerek *et al.* (2011) surveyed Swedish midwives attitudes (*n*=259) to maternal refusal of emergency CS and found that most Swedish midwives focused on fetal outcomes, rather than maternal autonomy, and therefore felt obstetricians should try to persuade the woman to agree to a recommended CS. It was also interesting that Danerek *et al.* (2011) asked midwives about their views of what obstetricians should do, rather than about midwives’ views of their own role and professional responsibilities. Given these limitations, questions remain about midwives attitudes to providing care to women who decline to follow professional advice.

A recent Australian study compared obstetricians’ and midwives’ attitudes about women’s autonomy during pregnancy and birth (Kruske *et al.*, 2013). After surveying 281 Australian midwives and obstetricians, the study concluded that both professional groups had a poor understanding of legal accountability and that clinicians’ responses were inconsistently supportive of women’s right to autonomy during childbirth. Those findings suggest that despite the 20 years since Mair and Kenny’s (1996) study described above, and despite the growing clarity in case law, little may have changed in the attitudes of clinicians. Perhaps it is this poor understanding of legal accountability that explains the apparent readiness of some clinicians to override maternal autonomy, documented in the numerous studies discussed above. As a result, Kruske *et al.* (2013) called for additional guidance for clinicians on maternal decision making throughout maternity care.

Clinicians' experiences of maternal refusal

Clinicians experiences (rather than attitudes) of providing care to women who decline to follow professional advice have mostly been reported via case studies. These case studies illustrate the challenging nature of a much broader range of maternal refusals than the attitudinal studies described above, which focus almost exclusively on CS refusal. Case studies have documented clinicians' experiences of refusal of induction of labour (IOL; Dann, 2007), episiotomy (Perry *et al.*, 2002), blood products (Biscoe & Kidson-Gerber, 2015), aspects of routine intrapartum care (Avci, 2015; Curtis, 2010) and CS (Brass, 2012; Osuna *et al.*, 2015; Weiniger *et al.*, 2006) and arise from a range of national contexts, including New Zealand, USA, Australia, England, Spain, Turkey and Israel. It is apparent from these cases that refusal of recommended care may provoke anxiety, uncertainty and feelings of helplessness in clinicians.

Many of these case studies occurred in countries with important differences to the Australian context. Dann (2007, p. 634) documented the "dilemma" experienced by a midwife and doctor in New Zealand who provided care to a woman who persistently declined IOL, despite clinical indication. Dann (2007) noted the particular impact of New Zealand's partnership model of midwifery, which calls for midwives to work with women and their families in a partnership of trust and shared decision-making and responsibility (Guilliland & Pairman, 2010). Despite this model, Dann (2007, p. 638) described a lack "ethical support for midwives when women make autonomous decisions that leave the midwife morally stressed." A second case study discussed a midwife's responsibilities in a fictional English case of a woman intending to attempt a VBAC at home, where the fetus was presenting in the breech position (Brass, 2012). Along with communication and documentation, Brass (2012) emphasised the importance of the Supervisor of Midwives. Statutory Supervision of Midwives, although currently undergoing major changes in the UK (Department of Health, 2016), was a process whereby midwives were supported in clinical practice, including support for both midwives and women making difficult decisions and advocacy for women who declined recommended care (Murphy, 2016; Read & Wallace, 2014). The partnership model and the accessibility of statutory supervision are both peculiar to the national contexts in which these two case studies were written. However, they were the only two papers found to examine the role and responsibilities of midwives.

Two other case studies (Perry *et al.*, 2002; Weiniger *et al.*, 2006) emphasised the importance of timely discussion with women, and the need for institutional policies and processes to enable such discussions. Perry *et al.* (2002) described the care provided to a woman whose birth plan conveyed that she would not consent to an episiotomy. Although the woman's birth plan was discussed with her obstetrician, a different doctor attended her birth and required the woman to consent to an episiotomy. It is unclear to what extent Perry *et al.* (2002) based their article on an actual case, however, the authors use the situation to demonstrate the importance of mutual trust and open communication while recognising "that institutional factors must be in place… to make such conversations possible" (p. 13). A similar conclusion was drawn by Weiniger *et al.* (2006) out of their case study of a woman who declined emergency CS because she was unable to consult with a rabbi. Although the specifics of the case are unique to its Orthodox Jewish context, the authors' conclusion that earlier discussion with the woman about her needs could have averted the crisis is more widely relevant and echoed in other studies (see Belaouchi *et al.*, 2016; Zeybek *et al.*, 2016). Weiniger *et al.* (2006, p. 147) called for "comprehensive hospital guidelines" to assist clinicians navigating such complex situations.

Perry *et al.*'s (2002) case report is also valuable for its demonstration of the complexities of fragmented care and medical autonomy, where an agreement with one doctor might not be accepted by a subsequent care provider. Perry *et al.* (2002) agreed that each doctor had the right to conscientious objection, but questioned whether refusal of recommended care could justify invoking it. The commitment to respect a patient's informed decisions may be just as pressing as "the conscientious commitment to preserve the lives and health of the patient and her child" (Perry *et al.*, 2002, p. 13). While Perry *et al.* (2002) acknowledged that when women decline to follow professional advice they may infringe on their care provider's autonomy, they concluded that "the risk from infringement on autonomy is greater for the patient, than the professional" (Perry *et al.*, 2002, p. 13). Despite this conclusion, they then raised the spectre of litigation, suggesting that it is "unfair to require physicians to practice contrary to the minimal standards of their training and yet hold them accountable for bad outcomes" (p.13). This conclusion may misrepresent medico-legal liability, which is more likely to arise from negligence, such as inadequately informing the woman about the risks attending her refusal or providing inadequate care within the confines of the woman's consent (White *et al.*, 2010). Perry *et al.* (2002) missed an opportunity to reiterate that coercing a woman to accept recommended care also carries liability (Kotaska, 2017), as seen in a recent US case (see Improving Birth, 2017).

One Australian case report (Biscoe & Kidson-Gerber, 2015) was also significant because it singularly considered a case with the poorest of all outcomes: maternal and fetal death. The paper described the care of a pregnant Jehovah's Witness woman with pre-eclampsia and a form of leukaemia. As her condition deteriorated, the woman maintained her informed refusal of blood products, which the authors concluded "undoubtedly contributed to the death of mother and foetus" (Biscoe & Kidson-Gerber, 2015, p. 462). Although the woman's right to refuse blood products was respected, the authors cited doctors' moral obligations to both the pregnant woman and her fetus and concluded that "the right of a mother to refuse… interventions on behalf of her foetus is more controversial" (Biscoe & Kidson-Gerber, 2015, p. 462). Such conclusions provide further evidence of an emerging clinical discourse which treats the fetus as a separate patient (as discussed earlier). The perception that controversy remains around a right that has repeatedly been upheld in legal decisions (and was also respected in this case) has considerable implications for women's autonomy.

Another case report (Avci, 2015) described the care of a woman in a Turkish public hospital in 2005. The woman was described as refusing to cooperate with clinicians, and the case report documents a range of disrespectful maternity care that followed. The woman ultimately left the hospital at full cervical dilatation and birthed soon after in another hospital, but her baby died two days later as a result of injuries incurred during the prolonged labour. Avci (2015) argues that the clinicians used simplistic understandings of the woman's right to autonomy to justify turning her out of the hospital. They concluded that "this conflict [and the poor outcome] substantially stemmed from the caregivers' misbehaviour, not treating the mother with dignity and respect, and the obstetrician's incorrect judgment regarding ethical issues, rather than [from] the mother's individual decision [to leave the hospital]" (Avci, 2015, p. 74). Such strong conclusions highlight the importance of building clinicians' understanding of women's rights to autonomy and supporting them to maintain respectful care practices when women decline to follow their advice.

Midwives' experiences

Two UK studies reported on the experiences of midwives who had provided care to women who had declined to follow professional advice, in some cases with poor fetal outcomes. Symon *et al.* (2010) interviewed midwives about, and reviewed clinical records associated with, 15 UK cases where maternal refusal was thought to have contributed to perinatal deaths. This study was significant because it was one of the few to consider the impact of a broad range of maternal refusals, including refusing antenatal screening. Although causes of death remained unexplained in several cases (due to the absence of post mortem results), the midwives interviewed perceived that seven of the fifteen deaths were not preventable, but that CS may have altered the outcome for the remaining eight. The study's review of clinical records concluded that midwifery care had been clinically acceptable, although constrained by the limitations of the women's consent. On that basis, Symon *et al.* (2010, p. 280) concluded that "if reality is to match rhetoric about 'patient' autonomy, such decision making in high-risk situations must be accepted."

A later study interviewed ten midwives about their experiences of providing care to women who had declined to follow professional advice (Thompson, 2013). The midwives in Thompson's (2013) study characterised women's refusals as seeking less intervention. Although this challenged the midwives' ability to fully assess the women's well-being, the participants reported that the women generally still had good outcomes. These midwives also valued engagement with their Supervisor of Midwives to develop individualised care plans. Thompson (2013, p. 566) found midwives used mainly negative words to describe their own experiences, invoking feelings of "frustration, stress and vulnerability." Despite these negative feelings, which were similarly reported by Symon *et al.* (2010), and in many of the case studies discussed above, midwives felt that their continued involvement was the best way to keep the women engaged in maternity care and secure the best possible outcomes under the circumstances.

Although not exclusively focused on the experiences of midwives, Roth *et al.*'s (2014) survey of doulas, childbirth educators, and labour and delivery nurses (*n*=1768) in North America had similarly concerning findings. More than half of the survey respondents had witnessed procedures performed despite a woman's explicit refusal, and almost two-thirds perceived that procedures were at least occasionally performed without giving women a choice or time to consider the procedure. Nearly one-third of respondents reported that women were at least occasionally told that their baby would die if they didn't accept recommended care. While these findings highlight how difficult it may be for women to decline recommended care, Roth *et al.* (2014) did not survey participants about how they had responded in these situations, nor whether they regarded these experiences as unacceptable ethical breaches.

Another study (Schorn, 2007) surveyed 111 certified nurse-midwives (CNMs) in the USA about their practices and beliefs about unilaterally discharging clients from their practice. Schorn (2007) found that 61.4% of CNMs had unilaterally discharged women from their care, including instances of doing so *during* labour and birth. The majority of CNMs surveyed (77.5%) also reported that would consider unilaterally discharging women from their care under certain circumstances, such as non-compliance (*n*=71, 64%), failure to keep appointments (*n*=63, 57%), unethical request (*n*=57, 51%), medically inappropriate request (*n*=57, 51%), refusal of recommended care (*n*=44, 40%), the woman's desires conflicting with practice philosophy (*n*=38, 34%), moral conflict (*n*=32, 29%), perceiving the woman to be uncooperative (*n*=31, 28%). Schorn (2007) survey did not appear to elicit information about how CNMs distinguished between these circumstances, nor did the discussion examine the impact of unilateral discharge on women's rights to decline recommended care. Interestingly, other studies (Ande *et al.*, 2010; Borkan, 2010; Ireland *et al.*, 2011) have linked behaviours such as missing appointments, with refusing recommended care (discussed further below), suggesting that perhaps many of the responses to Schorn's (2007) survey may have been related to that single phenomenon. Also, Schorn's (2007) own participants, as well as other studies discussed above (Avci, 2015; Chigbu & Iloabachie, 2007), reported adverse outcomes following this kind of withdrawal of care, which may also expose clinicians to greater medico-legal risk (Sujdak Mackiewicz & Thompson, 2017). Given that the study was conducted in the USA where medicalisation of childbirth and the perception of the fetus as a separate patient may be at their most pervasive, midwives elsewhere may have very different experiences and attitudes. Indeed, Schorn (2007) promulgated a 'two patient' perception of midwifery care, and differentiated between "respecting" and "supporting" women's choices: "sometimes it [a woman's decision] may be respected but not supported because of a conflict with other ethical principles, such as beneficence and non-maleficence… a clinician is not obligated to carry out a client's wishes if the clinician considers those wishes to be dangerous" (Schorn, 2007, p. 466). Such conclusions fail to distinguish between requesting and refusing care (discussed in Chapter One) and overlook the importance of a harm minimisation approach (discussed further below).

Women's perspectives

The perspectives of women who decline recommended maternity care have received relatively little attention in the literature. Even in the judicial decisions that have authorised CS on non-consenting women, women's voices are absent or discounted, with decisions often made within hours of application, often *ex parte*[1] and with clinicians' and even the woman's partner's evidence accorded more weight than her own (Adams *et al.*, 2003; Ikemoto, 1991). Several studies include women

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[1] An *ex parte* decision is one decided in a court without requiring all of the parties to be present (White *et al.*, 2010). In this case, it refers to decisions made when women were not present, not represented and in some cases, not aware of the proceedings.

who had declined recommended care, but each of them were conducted either in low resource settings (Chigbu & Iloabachie, 2007; Enabudoso *et al.*, 2011; Ugwu & de Kok, 2015), or with vulnerable groups of women such as Indigenous women living in remote Australia (Ireland *et al.*, 2011) or Somali women living in the USA (Borkan, 2010).

Chigbu and Iloabachie (2007) interviewed 62 women in Nigeria who declined recommended CS and concluded that their refusals were prompted by the fear of death as a result of the CS, financial reasons, the desire to experience a vaginal birth or inadequate counselling. In a second Nigerian study, Enabudoso *et al.* (2011) surveyed 139 pregnant women with a previous CS about their attitude towards repeat CS and found that 25% of the women would decline repeat CS if it was recommended. The reasons given by the women included concerns about postoperative pain, complications, cost, and social stigma. Enabudoso *et al.* (2011) called for health services to improve pain relief options and counselling about the safety of modern obstetric procedures and for governments to develop functional national health insurance to address the financial burden of CS. However, no recommendations addressed how to provide care to women who continued to decline CS, which may remain likely given the role of social stigma in women's decision making.

In the one Australian study located, Ireland *et al.* (2011) interviewed Australian Indigenous women and their family members (*n*=13) where the women had avoided routine transfer to urban hospitals, preferring to birth in their remote community. In that study, the women viewed being removed from their community, family, partner and children, sometimes for weeks at a time, to await birth in the city as much riskier than 'freebirthing' (planned birth without skilled attendant) or presenting to the remote clinic in established labour knowing it would be too late to be transferred by air to the referral hospital. The women's decisions to remain in their remote community for birth were based on previous negative experiences of waiting and birthing in the city, as well as their understanding of their own well-being, their baby's well-being and the needs of their older children (Ireland *et al.*, 2011).

Another relevant study focused on CS refusal amongst Somali women living in the USA (Borkan, 2010). An anthropological study, it involved four focus groups and 15 interviews and found that the women were acutely aware of their relative disempowerment in the health system, but nonetheless deployed active strategies to maintain control over their bodies and ensure vaginal births. The women reported seeking out midwifery care (as they regarded this as a guarantee of a vaginal birth), avoiding prenatal care, delaying their arrival to the hospital in order to avoid CS. They also reported changing care providers to find someone willing to support a vaginal birth in their situation. Borkan

(2010, p. 78) concluded that "Somali women do not agree on the definition of a successful birth, or on the measures that must be taken in order to achieve one… whereas providers conceive of c-sections resulting in a live newborn to be a healthy birth, many of the Somali women regarded them as disastrous."

While these studies collectively shed some light on women's reasons for refusing recommended care, and particularly on the need for culturally safe maternity care, they did not investigate women's interactions with the health system or clinicians. Another Nigerian study (Ugwu & de Kok, 2015) did examine clinical records and included interviews (*n*=29) with women, their husbands, nurses/midwives and doctors about CS refusal. Ugwu and de Kok (2015) reported high rates of CS refusal (with 22% of maternity clients refusing CS) which, as in other Nigerian studies discussed above, was linked to social stigma associated with CS. However, Ugwu and de Kok (2015) did not collect women's firsthand accounts of refusal. That is, while they interviewed women, none of the participants had themselves refused recommended care.

Some large survey studies have also elicited information about women's experiences of refusing recommended care. In Vedam, Stoll, Rubashkin *et al.*'s Vedam, Stoll, Rubashkin, *et al.* (2017) report on the development of the Mothers on Respect Index in Canada, concerning numbers of women (10% of 3884 women) reported feeling coerced into accepting recommended care. The study was replicated across three samples of women, with between 6.4% and 10.5% reporting that they had received poor care due to disagreeing with care providers about the right care for themselves or their baby (Vedam, Stoll, Rubashkin, *et al.*, 2017). Similar findings were reported in the Listening to Mothers Study III (*n*=2400) survey in the USA where although 21% of women had declined recommended care, 20% of women perceived that they had been treated poorly at least sometimes because of these disagreements (Declercq *et al.*, 2013). These large population level surveys paint a disturbing picture of the conflict women may encounter if they decline recommended care, but they were not designed to explore the underlying reasons for disrespectful care nor did they seek to reconcile women's and clinicians' experiences.

The literature on women's experiences of choosing homebirth is also relevant, given that homebirth is "one example of a patient choice that might differ from what a provider feels is in a woman's best interests" (Ecker & Minkoff, 2011, p. 1179). It may be particularly salient when women transfer from planned homebirths to hospital births, which Vedam, Stoll, Rubashkin, *et al.* (2017) reported was more likely to be associated with disrespectful maternity care than women remaining in either setting. Such disparities are concerning because apprehension about the reception they will receive at the hospital may lead women to delay or refuse transfer from home, even when it would be safer to do so, just as similar concerns in low-resource settings deter women from seeking skilled birth attendance (Kujawski *et al.*, 2015).

There is a body of literature suggesting that hospital maternity care is regarded by some women as unable to accommodate their birth intentions and that concerns over losing autonomy and control lead some to choose homebirth or freebirth (Holten & de Miranda, 2016). In Finland (Jouhki, 2012), Sweden (Lindgren *et al.*, 2010) and Scotland (Edwards, 2005), studies of women who planned homebirths found preservation of personal autonomy was an important motivator. In many cases, previous negative birth experiences, involving a loss of autonomy, shaped the women's decisions. While women perceived that homebirth carried a risk of being unable to access medical care if needed, they saw this as serious but unlikely, whereas the risks to their autonomy in a hospital setting were viewed as both serious and probable (Lindgren *et al.*, 2010). Similar findings emerged from Jackson *et al.*'s (2012, p. 561) study of twenty women who had chosen to "birth outside the system", a phenomenon which included both freebirth and planned, midwife-attended homebirth in the presence of identified medical risks factors. These women adopted broader definitions of risk and safety and perceived that hospital was a less safe place for them to birth.

Some studies have also indicated that women may conceal their intentions from care providers in order to avoid scrutiny and criticism. In Lindgren *et al.*'s (2010) study with homebirthing women, more than half of the women reported using avoidance strategies when interacting with obstetricians and hospital midwives, in order to avoid confrontation about their birth place decision. Similarly, in Ireland *et al.*'s (2011) study with remote-dwelling Australian Aboriginal women (discussed earlier), the women described how they had concealed their intentions from local clinicians, and in one case, avoided antenatal care altogether because they believed that they would be compelled to transfer. Likewise, both Ugwu and de Kok's (2015) study of CS refusal in Nigeria, and Borkan's (2010) study of CS refusal in Somali women living in the USA, documented a tendency for women to delay engagement with maternity care, especially during labour, as this was regarded as a strategy to avoid an unwanted CS. This kind of avoidance may be indicative of a crisis of trust and is concerning given the high value ethicists and clinicians may place on having on timely discussion with women about the risks of declining recommended care.

None of the case studies discussed earlier in this chapter gave voice to the women's experiences of the situations, although the two UK studies of midwives' experiences reported on midwives' perceptions of women's experiences (Symon *et al.*, 2010; Thompson, 2013). In both studies, midwives perceived that previous negative birth experiences led the women to seek greater control over a subsequent birth by declining interventions during pregnancy or labour, or transfer to hospital from home. Symon *et al.* (2010) also found that midwives perceived that women took responsibility for potentially poor outcomes when they declined recommended care, including refusing to transfer to hospital from a planned homebirth. However similar Australian cases, involving poor fetal or maternal outcomes following in labour transfer to hospital from home, indicate that women and their families may later question whether they received appropriate information about the implications of their choices (see Coroners Court of Victoria, 2013, 2016; Madden, 2014). There is a pressing need to directly include the voices of women who decline recommended care in research in order to better understand the phenomena of maternal refusal, and to determine how to provide high quality, woman-centred maternity care in that context.

Characteristics of women who decline recommended care

Several studies have also sought to document the characteristics of women who decline recommended care. Two Israeli studies (Iris *et al.*, 2009; Ribak *et al.*, 2011) examined the characteristics of women who declined medical intervention during labour and birth, and two US studies examined discharge from hospital against medical advice (Fiscella *et al.*, 2007; Tucker Edmonds *et al.*, 2014). In the Israeli studies, Iris *et al.* (2009) included women who refused CS or blood transfusion (without specifying indications), while Ribak *et al.* (2011) included women who refused emergency CS due to non-reassuring fetal heart patterns. Both studies were population-based and found that women who declined medical intervention were usually older, of higher parity and more likely to be members of a minority ethnic group than women who did not refuse treatment. Treatment refusal was also most common amongst women with complicated pregnancies. Similar findings emerged from the US studies, with both Tucker Edmonds *et al.* (2014) and Fiscella *et al.* (2007) finding that although rare in pregnant and postnatal women, discharge against medical advice was associated with various dimensions of disadvantage; factors such as race, insurance status and substance use or other mental health diagnoses were found to be predictors. Given that all four studies relied on *a priori* recorded categorisation of women as either discharging themselves against medical advice or declining recommended maternity care, it is unclear to what extent clinician attitudes could have influenced the categorisations and therefore the findings of these studies. The over-representation of disadvantaged women may actually be an artefact. Non-compliance may be more tolerated amongst women with higher levels of socio-economic advantage (Katz Rothman, 2014; Samuels *et al.*, 2007). Conversely, disadvantaged women may be more closely scrutinised (Harris, 2001) rather than actually being more likely to decline recommended maternity care.

This hypothesis, that disadvantaged women may be more scrutinised, is supported by a similar over-representation of disadvantaged women reported in a comprehensive review of arrests and forced interventions on pregnant women in the USA between 1973 and 2005 (Paltrow & Flavin, 2013). Where the cases did not relate to abortion access, the factors used to justify state intervention (either incarcerating women or authorising intervention on them) were examples of declining to follow professional advice, such as not attending antenatal care, birthing outside of hospital, drug use and refusing CS. Disadvantaged women were more likely to be singled out for judicial scrutiny, with women of colour, substance-using women and women of low socioeconomic status over-represented. Given that these women frequently came to the attention of authorities as a result of notifications made by medical staff, it is interesting to note the correlation between these findings and those in two other studies discussed above. Samuels *et al.*'s (2007) found that characteristics of the woman, rather than her medical risk profile, influenced clinicians' responses to her decision to decline recommended care, and their willingness to seek court-authorisation to impose CS without the woman's consent. Likewise, Vedam, Stoll, Rubashkin, *et al.* (2017) found women with self-reported medical and social risk factors, as well as recent immigrants or refugees, were most likely to experience high levels of disrespectful maternity care than their more advantaged counterparts.

Perinatal outcomes in women who decline recommended care

Some attention has also been given to the perinatal outcomes of women who declined recommended maternity care, consistently reporting poorer perinatal outcomes. The two Israeli studies described above (Iris *et al.*, 2009; Ribak *et al.*, 2011) examined documented cases of maternal refusal in one tertiary hospital between 1988 and 2002 (n=1898, out of 164064 births; Iris *et al.*, 2009) or between 1988 and 2009 (n=203, out of 10944 women who were advised to have a CS; Ribak *et al.*, 2011). Both studies included women in the refusal group, even if they subsequently consented to recommended treatment, and found that refusal of treatment was an independent risk factor for perinatal mortality. Ribak *et al.* (2011) also identified a trend towards higher rates of adverse perinatal outcomes where the delay between recommendation and consent to treatment was greater than 20 minutes. A Dutch study similarly examined the outcomes of Jehovah's Witnesses women who had declined blood products (van Wolfswinkel *et al.*, 2009). After reviewing all cases of maternal mortality in The Netherlands between 1983 and 2006, and all cases of serious maternal morbidity between 2004 and 2006, van Wolfswinkel *et al.* (2009) concluded that Jehovah's Witness women were at 130 times greater risk of maternal death, and more than three times greater risk of serious morbidity due to obstetric haemorrhage. Finally, one of the US studies which investigated discharge against medical advice discussed above (Tucker Edmonds *et al.*, 2014) also reported on the outcomes of women in their study. In that study, antenatal discharge against medical advice was associated with poorer perinatal outcomes, depending on the diagnosis. For example, Tucker Edmonds *et al.* (2014) reported that women with pregnancy-induced hypertension were at three times greater risk of fetal death, while those admitted with preterm rupture of membranes were at significantly increased risk of birthing infants small for gestational age (OR 1.47), and neonatal respiratory distress (OR 1.35); however the study was limited by the inability to examine the impact of provider or health service factors.

Two Nigerian studies have also reported on the outcomes of women who declined recommended maternity care. Chigbu and Iloabachie (2007), discussed earlier, identified women who had refused CS between 2004-2006 and created a control group of women who consented to CS during the study period in the same hospitals in Nigeria, matched for age, parity, education, employment and indication for CS. They found high rates of CS refusal, with 11.6% of women refusing recommended CS. Both maternal mortality and perinatal mortality were significantly higher in the refusal group (15%, and 35%, respectively) than in the control group (2% and 5% respectively). However, the CS indications included in that study were regarded as absolute, and obstetricians subsequently withdrew care. This policy forced the women to seek care at health facilities without emergency obstetric care provision, which the authors implicated in the poor outcomes. A similar methodology was used by Ande *et al.* (2010) in a prospective matched case control study of women who did not keep appointments for IOL in Nigeria (*n*=92). Although the clinical outcomes of women who did not keep appointments were not significantly different from those that were induced, Ande *et al.* (2010) concluded that not keeping an appointment for IOL was most commonly a result of preferring to wait for the spontaneous onset of labour (56.6%). This finding is similar to the studies of women's perspectives discussed above (Borkan, 2010; Ireland *et al.*, 2011; Lindgren *et al.*, 2010) that identified women's use of avoidance strategies, rather than overt refusals.

The homebirth literature is also informative with regard to the perinatal outcomes of women who decline recommended maternity care. While numerous studies have shown that planned homebirth amongst low-risk women is associated with lower rates of intervention, without compromising maternal or fetal safety (Bastian *et al.*, 1998; Brocklehurst *et al.*, 2011; de Jonge *et al.*, 2009; Olsen & Clausen, 2012), the same cannot be said when women with identified obstetric risk factors birth at home. Both Australian (Bastian *et al.*, 1998; Kennare *et al.*, 2010) and international studies (Mehl-Madrona & Mehl Madrona, 1997) have found that homebirth after 42 weeks gestation, or with twins or a breech presenting baby was associated with higher rates of neonatal mortality. A further UK study (Symon *et al.*, 2009) identified a significantly greater rate of stillbirth and neonatal death amongst 1,462 women who laboured and birthed under the care of private midwives in the UK (*n*=1,462), compared with a matched cohort of women who had birthed within the National Health Service (*n*=7,214). Most of the women receiving private midwifery care had planned homebirths, and the disparity in neonatal outcomes disappeared if women with pre-existing medical and obstetric risk factors (irrespective of neonatal outcome) were excluded.

Possible consequences of inflexible maternity care

It is the possibility of disengagement from mainstream hospital maternity care, and the associated poor perinatal outcomes, that has led many authors to call for a harm minimisation approach when women decline recommended maternity care. In the aforementioned study, Ireland *et al.* (2011) called for more flexibility than the current policy of mandatory transfer to urban centres for birth. Given that approximately 10% of women in some remote Australian Aboriginal communities birth outside of hospital, Ireland *et al.* (2011, p. 640) concluded: "the safer option would be to sanction community birth services and provide holistic midwifery care." Likewise, Chigbu and Iloabachie (2007) responded to the higher maternal mortality rate documented in their study by calling for health service policies and processes to accommodate the care of women who declined to follow professional advice. They concluded that such frameworks would offer medico-legal protection to clinicians, allow them to continue to provide care and thus preserve women's access to emergency obstetric care: "There should be a way of accommodating the wishes of these women within our tertiary hospitals within the framework of acceptable good obstetric practice" (Chigbu & Iloabachie, 2007, p. 1264). Ecker and Minkoff (2011) argue against doctor's refusing to care for women whose birth intentions they perceive to be excessively 'risky', concluding that "many, if not most, medical choices will be made safer by a physician's participation" (Ecker & Minkoff, 2011, p. 1179; see also Kotaska, 2017). Even ethicists who argue that women have a moral obligation to birth in a hospital (rather than at home) stop short of proposing bans on homebirth or legal sanctions for women who choose that option. Instead, they concede that "the best solution is to make hospital-based delivery more acceptable to women" (de Crespigny & Savulescu, 2014, p. 810), a solution which must surely address the apparent crisis of trust in hospital maternity amongst at least some women. Dahlen *et al.* (2011, p. 49) argue that contemporary maternity care is “broken” with inflexibility rendering it unable meet women’s needs and contributing to recent rises in the number of women choosing freebirth or employing a doula for hospital births.

Guidance for clinicians

Many of the studies reviewed here have called for additional guidance for clinicians and often, a harm minimisation approach. However, a purposive search of the websites and publications of Australian, New Zealand, UK, USA and Canadian national midwifery and obstetric organisations revealed that guidance for clinicians about the care of women who decline to follow professional advice is limited and ambiguous. Only the American College of Obstetricians & Gynaecologists (ACOG, 2016) and the Australian Medical Association (AMA, 2013) have current position statements that specifically focus on the topic of refusing recommended maternity care.[2] In other cases, the issue of refusal is addressed in general terms within documents that guide clinicians on matters such as informed consent (Royal Australian and New Zealand College of Obstetricians and Gynaecologists (RANZCOG), 2013, 2016; Royal College of Obstetricians and Gynaecologists (RCOG), 2015), shared decision making (American College of Nurse Midwives (ACNM), 2016) and models of care (Canadian Association of Midwives (CAM), 2013, 2015). These documents, along with the ethical codes of practice for clinicians in each setting and internationally, emphasise informed consent and respect for patient autonomy (see ACNM, 2013; ACOG, 2011; Canadian Medical Association, 2004; Canadian Midwifery Regulators Council, 2000; FIGO, 2003; International Confederation of Midwives (ICM), 2014; New Zealand College of Midwives, 2017; Australian Nursing and Midwifery Council, 2008; RANZCOG, 2006b). They do not, however, guide clinicians on the appropriate clinical responses when women decline recommended care. Some scholars have argued that this situation leaves clinicians with an unresolved ethical conflict when women decline recommended care (Cuttini *et al.*, 2006; Holten & de Miranda, 2016).

Midwifery and obstetric codes and guidelines also recognise clinicians’ own autonomy rights, that is, their right to decline to participate when the care preferred by the patient is “nonstandard,

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[2] The Royal College of Obstetricians and Gynaecologists (RCOG, 2006) and Royal College of Midwives (RCM, 1999) have both also previously published position statements condemning the phenomenon of court-ordered obstetric intervention, but these statements are no longer available on their respective websites.

nonbeneficial or harmful… or would betray their consciences" (Minkoff *et al.*, 2014, p. 1101). Conscientious objection is most often invoked in debates around access to abortion or contraception, but it is also probable that clinicians' personal beliefs about the moral standing of the fetus influence their decisions in cases of maternal refusal (Minkoff *et al.*, 2014). In this way, conscientious objection can conceal paternalism (Brazier, 2006) and is increasingly viewed as needing limits (ACOG, 2007; Fiala & Arthur, 2014; Fiala *et al.*, 2016; Harter, 2015). Nonetheless, clinicians might reasonably ask themselves "When does support for patient choice and autonomy become support for poor decision making? When is participation not respectful but enabling?" (Ecker & Minkoff, 2011, p. 1179).

Unreasonably refusing care is rejected in some guidelines (RANZCOG, 2006b) yet it remains unclear when (if ever) it might be warranted or how this intersects with women's rights to autonomy. This is concerning since withdrawing from the care of a patient creates ethical and medico-legal risks for clinicians (Sujdak Mackiewicz & Thompson, 2017). In Australia, one professional indemnity insurer advises its members that "failure to follow medical advice is one commonly encountered situation where termination of the [doctor-patient] relationship may be required" (Medical Insurance Group of Australia, 2011, p. 1). Similar advice is offered to midwives from the same insurer (Medical Insurance Group of Australia, 2013). Despite the scholarly support for harm minimisation approaches (discussed above), withdrawing care may also be seen as the appropriate response if a woman's decisions raise scope of practice issues for the clinician. However, scope of practice is treated very differently in different contexts. For example, the American College of Nurse Midwives (ACNM, 2016, p. 1, emphasis added) stipulates that "when [a woman's] decisions are in conflict with the clinical recommendation, the midwife *is not* obligated to compromise professional scope of practice in order to accommodate patients' preferences." Conversely, midwifery guidelines from both New Zealand (Ministry of Health, 2012) and Australia (ACM, 2014) were the only documents identified in this review that offer advice and a process for continuing to provide care to women when they decline to follow professional advice, even where that may see the clinician operating outside their experience or scope of practice. In all other cases, professional guidance for clinicians appears to be silent on the subject of continuing to provide care to women who decline to follow professional advice.

Policies or processes developed and evaluated in clinical settings are also rare in the literature. Four papers (Chervenak & McCullough, 1990; Deshpande & Oxford, 2012; Kotaska, 2017; Pinkerton & Finnerty, 1996) have described processes for managing a range of situations in which pregnant women may decline to follow advice. Until the publication of Kotaska's (2017) *Practical Ethical Guide* this year, the option of court intervention to sanction treatment on non-consenting women was accepted in these papers, although Deshpande and Oxford (2012, p.e149) recognised that there were "very few cases in which legal intervention may be appropriate." The earlier processes, published in 1996 (Pinkerton & Finnerty, 1996) and 1990 (Chervenak & McCullough, 1990) also include the option of withdrawing care, although this appears to be omitted in the more recent publications, where the authors stipulate that "the pregnant patient should always be offered hospital resources" (Deshpande & Oxford, 2012, p. e149). Kotaska (2017, p. 3) goes further again, likening withdrawal of care to abandonment and notes that as an effort to convince women to comply it is "a coercive and dangerous form of 'chicken' that is ethically inappropriate in modern health care."

Several other papers focus on the care of women who refuse blood products on religious grounds (Belaouchi *et al.*, 2016; Braithwaite *et al.*, 2010; Gupta *et al.*, 2012; Kidson-Gerber *et al.*, 2016; Mahoney & Valenti, 2004; Zeybek *et al.*, 2016). However, most of these focus on the clinical management of such women. Only Zeybek *et al.* (2016) offers advice about discussing, documenting and communicating about a woman's refusal of blood products. In particular, Zeybek *et al.* (2016) argue that clinicians must appreciate the distinction between a woman refusing a blood transfusion and a woman choosing death, refusing all care or being disinterested in alternative options. Zeybek *et al.* (2016) argue that failing to make this distinction is often at the root of clinicians refusing to treat women and missing opportunities to engage them in maternity care. Likewise, Zeybek *et al.* (2016, p. 497) call for approaches to documentation that alert other clinicians subsequently involved in the woman's care and "set a tone of mutual respect and recognition of the important role that nonmedical values play in the lives of patients." Although keenly focused on the particular situation of blood refusal, Zeybek *et al*.'s (2016) advice seems relevant to a wider range of situations in which women decline recommended maternity care.

However, whether concerned with the specifics of blood refusal or more broadly conceptualised refusals, none of these papers report on the utility of the processes they propose in clinical practice, nor on the experiences of clinicians or women using them. In their Australian study of medical negligence claims and patient complaints related to informed consent, "there remains remarkably little empirical information on how the consent process actually functions (and malfunctions) in clinical practice" (Gogos *et al.*, 2011, p. 340). Likewise, Holten and de Miranda (2016, p. 61) concluded that although there is a growing body of research that has examined the phenomenon of “birth outside the system”, there is a need for further research on the care of women “who are sceptic [sic], but remain inside the system” in order to address the apparent “lack of fit” between women’s individual needs and the maternity care system.

Conclusion

This review has demonstrated that literature concerning pregnant women who decline recommended care has been dominated by ethical debate about the status of the fetus and the attitudes of obstetricians to court intervention. Scholarly attention, in parallel with judicial decisions, has focused on refusal of CS and, to a lesser extent, blood products. Given that professional guidance cautions clinicians against recourse to court intervention, questions remain about the experiences of obstetricians, midwives and women in maternity care settings when women decline recommended care. Sizeable minorities of obstetricians and midwives continue to report equivocal respect for maternal autonomy. This literature review has highlighted the ethical and moral turmoil experienced by clinicians and documented the often poorer clinical outcomes of women who decline recommended maternity care. However, neither of these phenomena diminish a pregnant woman’s right to decline recommended care. Women’s voices have been omitted from the literature on this topic, although it is apparent that concerns about loss of autonomy drive some women to disengage from mainstream maternity care. Numerous studies have concluded that greater guidance and support is needed for clinicians, yet the professional guidance available to clinicians remains limited and ambiguous. Processes to discuss and document refusal with women have been theorised in the literature and described in some midwifery guidelines, but they do not appear to have been systematically studied in clinical practice.

Chapter Three: Research Design and Methodology

Introduction

The preceding chapters have explored the reasons why declining recommended maternity care may provoke tension and conflict between women, clinicians and, in some cases, the state. The literature on this topic largely excludes both women's experiences and the role and value of non-coercive systems-level processes to discuss and document refusal. Now, this chapter describes the research design and methodology that guided the conduct of this study. This chapter will situate the study within the overall domain of Health Services Research (HSR), and establish how it is shaped by the transformative paradigm and a feminist theoretical framework. It will describe the appropriateness and use of the mixed methods design and discuss the major ethical considerations in the conduct of this study.

Research question and objectives

The overarching goal of this study was to support women's rights to decline recommended maternity care by promoting the need for systems-level responses to refusal.

The primary research question was: *Could a documentation and communication process support pregnant women's rights to decline recommended maternity care?*

This research question was addressed through the following objectives:

1. Review the processes and outcomes associated with a structured documentation and communication process used in one tertiary hospital (known as the Maternity Care Plan, or MCP, process).
2. Describe women's, midwives' and obstetricians' experiences of the MCP process.
3. Develop a feminist understanding of the experiences of women, midwives and obstetricians when women decline recommended maternity care in a hospital setting.
4. Describe an activism-oriented methodological approach that may be useful to researchers seeking to drive woman-centred systems-level reform in maternity services.
5. Make recommendations for policy, practice, education and research that could support respectful maternity care when women decline to follow professional advice.

Theoretical framework

Given that the overarching goal of this research was to support women's rights to decline recommended maternity care by promoting the need for systems-level responses to refusal, a pragmatic and applied approach was taken to all decisions regarding design, methods, analysis and dissemination. This included drawing on both HSR and the transformative paradigm. The following sections describe these two approaches and how they were applied in the context of this particular study.

Health Services Research

Health Services Research focuses on "how social factors, financing systems, organisational structures and processes, health technologies, and personal behaviours affect access to health care, the quality and cost of health care, and ultimately our health and well-being" (Lohr & Steinwachs, 2002, p. 16). In doing so, HSR aims to produce "reliable and valid research data on which to base appropriate, effective, cost-effective, efficient and acceptable health services" (Bowling, 2014, p. 18). This study was particularly focused on the quality and acceptability of health services, both of which are fundamental to patient-centredness: the provision of care in ways that are valued by and acceptable to patients (Horner *et al.*, 2013).

The landmark report, Crossing the Quality Chasm (Institute of Medicine (US), 2001) identified patient-centredness as one of six dimensions of quality in healthcare. Although there has been a growing emphasis on quality in healthcare and the importance of patient's involvement in decision making (Black, 2009), Berwick's (2005, p. 330) suggests that more research is needed to examine "what it is that makes the 'right' thing, the 'easy' thing to do." This study takes up that question with a particular focus on identifying and supporting systems-level processes that may make respecting women's rights to refuse recommended maternity care easy, or at least easier.

To date, published HSR has been dominated by positivist (quantitative) methods most familiar to and valued by clinicians and funders (O'Cathain *et al.*, 2007). While a "quiet revolution" (O'Cathain, 2009, p. 3) has seen the growing acceptance of qualitative methods, HSR remains dominated by the "biomedical paradigm and its social science offshoots" (Weber & Castellow, 2012, p. 2), where the artifice of objectivity leaves only limited capacity to tackle reform directly (Gilson *et al.*, 2011). A need remains to "think more deeply about how to support policy and system change through… research" (Gilson *et al.*, 2011, p4). So while systems-level processes to support women’s rights to refuse recommended maternity care should naturally sit within an HSR framework, such an activist orientation calls for additional strings to the theoretical bow. This thesis turns to the transformative paradigm to bridge this activism-scholarship divide (Weber & Castellow, 2012).

Transformative paradigm

The transformative paradigm informs the work of researchers seeking to “address inequality and injustice in society” (Mertens, 2007, p. 212). Transformative research references a problem in a community of concern, that is, a group whose members are in some way oppressed, marginalised, or underrepresented. Members of that community may initiate the study and be actively engaged in it and seek to produce data and outcomes that interrogate power relationships, facilitate social change and benefit their community (Sweetman *et al.*, 2010). It is this point which sets transformative research apart from translational. The aim of transformative research is not just the translation of research findings, but the conduct of research in ways that seek to benefit marginalised people. The transformative paradigm was applied in this research to promote the need for systems-level responses to refusal recommended maternity care, benefiting birthing women who are oppressed by medicalised maternity care.

Feminism & mothering

Transformative researchers may use many different theoretical lenses, including feminist, critical and disability rights theories (Mertens *et al.*, 2010). In this study, adopting a feminist theoretical lens allowed me to situate medicalised and institutionalised maternity care within the wider social milieu of women’s oppression and subordination, and recognise disrespectful maternity care as an issue of violence against women (Jewkes & Penn-Kekana, 2015; Sadler *et al.*, 2016). Feminist theory was essential to developing a critical understanding of the sharply gendered issues of power and control that come into play when women decline recommended maternity care.

Patriarchal[3] control of women’s bodies has long been a focus in feminism (Rich, 1995), particularly as women’s procreative capacities have been used to define and circumscribe the value of

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[3] Although the continuing use of the term patriarchy has been questioned (Budgeon, 2011), it remains, as Rich (1995, p. xxiii) suggested, “a useful concept… [and] a major form of domination parallel and interconnected to race and

femaleness (Katz Rothman, 1989; Rich, 1995). However, the feminist reproductive rights agenda has been narrowly defined, with attention falling almost exclusively on access to contraception and abortion (Roberts, 2003). The lack of feminist attention on pregnancy, childbirth and mothering reflects the seemingly anti-motherhood stance of second-wave feminism (O'Reilly *et al.*, 2005; Oakley, 1984). Partly this was of necessity – emphasising women's procreative capacities would have created space for essentialist arguments against the feminist campaign for workplace equality and access to childcare (Kevin, 2005; Reiger, 1999). Second wave feminists worked, in essence, to free women from obligatory motherhood, which was seen "as a significant, if not the determining, cause of women's oppression under patriarchy" (O'Reilly, 2014, para 13).

The marginalisation of mothers and mothering from feminism has persisted, however, even as the intersection of gender with other dimensions of a woman's oppression (such as race, class, sexuality) have given rise to more inclusive feminisms (O'Reilly, 2014). O'Reilly suggests that this reflects a "larger and pervasive feminist discomfort with all things maternal" (O'Reilly, 2014, para 13). Likewise, Katz Rothman (1989, p. 7) described motherhood as "awkward" for feminism, which had rejected patriarchal definitions of motherhood, but not developed a woman-centred way of looking at it.

Rich's (1995) landmark work, *Of woman born: motherhood as experience and institution*, distinguished "between two meanings of motherhood, one superimposed on the other: The *potential relationship* of any woman to her powers of reproduction; and the *institution*, which aims at ensuring that that potential – and all women – shall remain under male control" (Rich, 1995, p.13; emphasis in original). The *institution* of motherhood is unequivocally oppressive, a kind of "powerless responsibility" (Rich, 1995, p. 42) where women are defined by their motherhood and remain the object mistrust, suspicion and misogyny (Rich, 1995). Edwards and Murphy-Lawless (2006, p. 44) similarly describe this as the situation where "women in our postmodern, but still patriarchal, societies are often expected to take responsibility without the means to do so." Women who are seen to fail their children find their character and value as women called into question (Rich, 1995) because their only value is as the mothers of men's children (Katz Rothman, 1989). Rich's distinction between patriarchal motherhood and women's experiences of mothering demonstrated that by resisting the normative discourse, mothering could be woman-centred and

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class." It is in this sense that I use the term, because it captures an entrenched cultural and ideological pattern, that while evolving, remains significant.

empowering (O'Reilly, 2007). The solution then became not the renunciation of motherhood but its transformation (Tong, 2008). Rich’s distinction opened the way for the development of a matricentric feminist theory, which foregrounds maternal power and values mothering, as well as affording women “a life, purpose and identity outside and beyond motherhood” (O'Reilly, 2007, p.802).

Feminism and medicalised maternity care

Arguably the feminist transformation of motherhood should begin where motherhood begins: in pregnancy and childbirth. The medicalisation and institutionalisation of childbirth has been critiqued by numerous scholars for at least four decades, only some of whom are explicitly feminist (see Crossley, 2007; Davis-Floyd, 2008; Donnison, 1988; Katz Rothman, 1989; Keating & Fleming, 2009; Kirkham, 2004b; Murphy-Lawless, 1998; Newnham, 2014; O'Reilly *et al.*, 2005; Oakley, 1984; Rich, 1995; van Teijlingen *et al.*, 1999). The medicalisation and institutionalisation of childbirth has furthered patriarchal control of women’s bodies (O'Reilly *et al.*, 2005) and underpins women’s alienation from birth: Babies have come to be seen as the product of medical services, with ‘good outcomes’ defined only in terms of mortality and morbidity (Katz Rothman, 1989). In the era of evidence-based medicine, what counts as ‘evidence’ is mediated by a culture that favours technology and intervention, focusses on the short-term and trivialises women’s experiences (Wendland, 2007).

Cultural creation of the unborn child

One consequence of the medicalisation of pregnancy and childbirth has been the conceptual separation of the woman and the fetus she carries. Katz Rothman (1989, p. 79) describes this “cultural creation of the unborn child” as the most fundamental change in the reproductive rights debate since the 1920s. Feminist scholars have linked this personification of the fetus with the advent of antenatal care and with the increasing reliance on technology (Featherstone, 2008; Oakley, 1984). Auscultation of the fetal heart and ultrasound, for example, allow the fetus to be separately monitored and visualised, while the woman fades into the background (Featherstone, 2008). Likewise, the acceptance of caesarean section into obstetric practice enabled fetal rescue despite its initially appalling maternal mortality (Murphy-Lawless, 1998). As maternal mortality declined, medicine’s focus shifted to the preservation of fetal life (Featherstone, 2008) and pregnant women changed from being seen as protectors of the unborn to (at least) potential threats (Katz Rothman, 1989; Oakley, 1984). This separation of woman and fetus has long been a feature of patriarchy, but the medicalisation of pregnancy and childbirth has allowed this separation to become more concrete, and with that, for the fetus to be seen as a separate person and patient (Katz Rothman, 1989; Weitz, 2003).

This conceptual separation of woman and fetus has also allowed conservative social forces to promulgate the notion of fetal rights (Pollitt, 2003). Feminists have long challenged fetal rights in the narrow context of access to abortion,[4] but the anti-choice lobby has deployed fetal rights rhetoric more widely in order to regain ground ceded to feminism (Diaz-Tello, 2016b). “Fetal rights is all about controlling women … It is an index of deep discomfort with the notion of women as self-directed social beings, for whom parenthood is only one aspect of life, as it has always been for men" (Pollitt, 2003, p.298). As fetuses have acquired personhood, parenthood obligations have extended backwards into pregnancy (Bristow, 2016), and even preconception (see Clark-Flory, 2016). The powerless responsibility of patriarchal motherhood has been reasserted, holding women responsible for the well-being of children, including (and perhaps especially) the unborn. The patriarchal distrust of women also persists such that “it becomes then the burden of others to regulate those who cannot govern themselves” (Piering, 2013, p182-3).

Reclaiming the birth experience

Opposition to the medicalisation of childbirth arose in the 1960s, in the form of the natural childbirth movement. However, feminists regarded the natural childbirth movement with suspicion, observing that it was easily co-opted by biologically essentialist arguments about (patriarchal) family (Rich, 1995). Simultaneously, medicine has tended to dismiss birth activists as an “articulate minority … creating a false impression of mass discontent” (Oakley, 1984, p. 243). Although the limitations of the concept of satisfaction with maternity care are widely acknowledged (van Teijlingen *et al.*, 2003), some authors continue to link silence with satisfaction (McIntyre *et al.*, 2012). This equation of silence with satisfaction is common in the stance of dominant groups towards the oppressed (Oakley, 1984). Critiques of medicalised childbirth have also remained on

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[4] The medicalisation of abortion had many parallels with the medicalisation of childbirth. For example, it depended on the driving out of female, non-medical practitioners and resulted in curtailing of women’s rights to choose against the physician’s right to refuse to provide care (Featherstone, 2008; Katz Rothman, 1989).

the periphery of medical sociology (Oakley, 2016). In Australia (arguably even more so than in other places), the feminist movement remained remarkably silent on matters of maternity and the rift between feminism and mothers' organisations was marked (Kevin, 2005; Reiger, 1999). Women's struggles for reform have been readily dismissed as being personal rather than political (Gosden & Noble, 2000).

Nonetheless, matricentric feminists have sought to reclaim and value the birth experience as a valued rite of passage. Rich describes a feminist poster bearing the slogan: "I am woman giving birth to myself" noting the invocation of birth as a "process which is painful, chosen, purposive: the creation of the new" (Rich, 1995, p.156). A similar sentiment is echoed in the oft-quoted words of Roth Katzman (1996, p. 254): "Birth is not only about making babies. Birth is about making mothers... strong, competent, capable mothers who trust themselves and know their inner strength." Lintott (2013) went further, theorising that the experience of pregnancy and childbirth is consistent with a feminist conception of the sublime, involving the merging of negative and positive emotions, yielding a highly valued experience. This reclaiming of the birth experience changes women's relationship to fear and powerlessness not just in pregnancy and childbirth, but also as mothers (Rich, 1995).

Feminist health services research

Bringing feminism and HSR together creates some unique challenges. Some feminist scholars question the value of positivist approaches to research (Hesse-Biber, 2010), such as those traditionally valued in HSR. Progressive HSR scholars note that "the practices of health services research must be engineered to achieve the goal of valued health care" (Horner *et al.*, 2013, p. 1033), particularly healthcare valued by patients. This study answers both of these concerns by turning to mixed methods research.

Mixed methods research

Mixed methods research "focusses on collecting, analysing and mixing both quantitative and qualitative data in a single study or series of studies" (Creswell & Plano Clark, 2007, p. 5). Mixed methods are particularly appropriate in HSR when the questions under study are too complex or sensitive for the development of standardised instruments (Bowling, 2014). Bowling (2014) cites the example of disrespectful care practices as one example of such a sensitive and complex topic, which justifies their use in this study. This approach was also chosen because "mixed methods are tools for social transformation in women's lives. Numbers plus words are a powerful combination" that speaks to health service policy-makers and managers (Hesse-Biber, 2010, p. 22).

Mixed methods designs

There are at least four major designs recognised in mixed methods research: triangulation, embedded, explanatory and exploratory (Creswell & Plano Clark, 2007). Within those overall designs, variants exist around the timing, relative emphasis and mixing of data. In terms of timing, mixed methods designs permit qualitative data to be collected concurrently, or sequentially with quantitative data. Greater emphasis can be given to qualitative or quantitative data, or they can be emphasised equally. Data can be mixed by merging at various stages of analysis, embedding quantitative data in a qualitative design (or vice versa) or by connecting or requiring one kind of data to lead to the other (Creswell & Plano Clark, 2007).

Sequential explanatory design

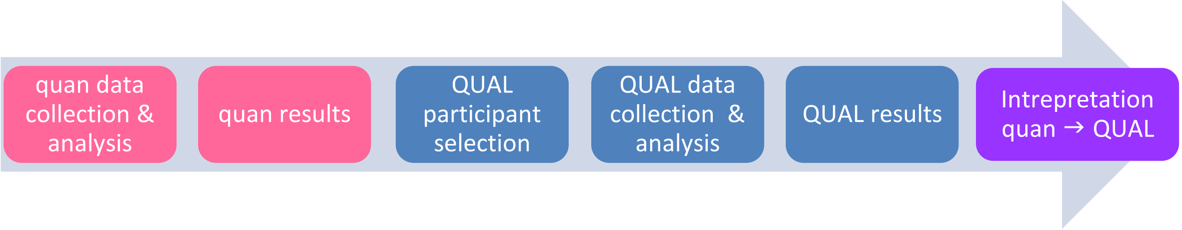

Figure 2: Sequential Explanatory Design (Participant selection model). Source: Creswell and Plano Clark (2007, p. 73).

The approach adopted in this study was a sequential, explanatory design (see Figure 2).[5] This approach has two distinct phases: a preliminary quantitative phase which is used to develop a general understanding of the problem, followed by a larger qualitative phase which elaborates on that quantitative data by exploring participants' views in depth. Creswell and Plano Clark (2007) describe two variants to this design: the follow-up explanations model and the participant selection model. These two models differ in the relative emphasis and purpose of the two phases. In the follow-up explanation model, a secondary qualitative phase is used to explain or expand on quantitative results (which are given primacy in the study). In the participant selection model, the

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[5] The use of the notation 'quan' and 'QUAL' in Figures 2 and 3 is as per Creswell and Plano Clark (2007), who use capitalisation to indicate the relative emphasis of the quantitative and qualitative phases.

quantitative data are collected first and inform purposive selection of participants for the more significant qualitative phase (Creswell & Plano Clark, 2007). This study followed the participant selection model (see Figure 2).

Quantitative phase

In this study, the quantitative phase (see Figure 3) involved a retrospective cohort study comprising chart audit, descriptive statistical analysis of routinely collected demographic data and clinical outcomes, and content analysis of Maternity Care Plans (MCPs). Beginning with a quantitative phase had three purposes. Firstly, it mapped the scope and use of the MCP process in its first three and half years of implementation. Secondly, the quantitative data underpinned the selection of participants for the subsequent qualitative phase. Thirdly, it ensured the production of data that doctors and health service policy makers were most likely to engage with and value. This is consistent with Hodgkin's (2008, p19) conclusion that researchers "seeking to influence the policy and practice agenda around women's issues might consider the types of data that are most highly regarded by the audience they are seeking to persuade."

Qualitative phase

The quantitative phase led to the subsequent qualitative phase by enabling the recruitment of women, midwives and obstetricians for semi-structured interviews, as per the participant selection model (Creswell & Plano Clark, 2007). In this study, the quantitative data underpinned the identification of prospective participants who had experienced the MCP process. This was a purposeful approach to sampling (Lincoln & Guba, 1985), with participants chosen for their potential to generate detailed accounts of the issues central to treatment refusal in maternity care. The purpose of the qualitative phase of the study was to explain and expand upon the initial quantitative data. The subsequent qualitative phase provided insights into participants' experiences of using the MCP process and of refusal more generally.

The qualitative data were given greater emphasis in this study for several reasons. Firstly, the quantitative data were drawn from a very small sample. Although this included all of the MCPs related to refusal of recommended care generated during the study period, the small sample size precluded causal inferences or conclusions about rare clinical outcomes. Such conclusions would also have been tangential to the study's goals, that is, this was not a study about whether the women's birth intentions were 'safe', but rather whether a structured documentation and communication process could support their autonomy. Thus, the qualitative data were more

quan data collection and analysis

- Retrospective cohort study, involving chart audit, descriptive statistical analysis of demographic data and clinical outcomes, and content analysis of MCPs.

quan results

- Published paper (see Chapter Four): Jenkinson, B., Kruske, S., Stapleton, H., Beckmann, M., Reynolds, M., Kildea, S. (2015). Maternity Care Plans: A retrospective review of a process aiming to support women who decline standard care. *Women Birth*, 28(4): 303-309.

QUAL participant selection

- Content analysis of MCPs to identify women who had declined recommended care, combined with chart audit to identify those who had consented to be contacted about research.
- Purposive recruitment of midwives and obstetricians, to reflect experience of MCP process (as documented in MCP database) and context of practice (antenatal clinic, birth suite, continuity model of care).

QUAL data collection

- Semi-structured interviews with women, midwives and obstetricians.

QUAL data analysis

- Two iterations of thematic analysis: descriptive thematic analysis and feminist thematic analysis.

QUAL results

- Published paper (results of descriptive thematic analysis, see Chapter Five): Jenkinson, B., Kruske, S., Stapleton, H., Beckmann, M., Reynolds, M., Kildea, S. (2016) Women's, midwives' and obstetricians' experiences of a structured process to document refusal of recommended maternity care. *Women Birth*. 29(6), 531-541.
- Published paper (results of feminist thematic analysis, see Chapter Six): Jenkinson, B., Kruske, S., and Kildea, S., (2017). The experiences of women, midwives and obstetricians when women decline recommended maternity care: A feminist analysis. *Midwifery*. 52, 1-10

Interpretation quan →QUAL

- Synthesis of quantitative and qualitative data within the feminist and HSR frameworks to provide deeper understanding of the results and the role of research as a driver of reform.
- Submitted paper (applying the tenets of transformative/feminist research to the context of health services research to describe a new methodological approach, see Chapter Seven): Jenkinson, B., S. Kruske and S. Kildea (under review). Legitimising agenda-driven research to support change in maternity services. *Qual Health Res.*
- Synthesis of the study as a whole and identification of systems-level recommendations to support women's rights in maternity care (Chapter Eight).

Figure 3: Sequential explanatory design as applied to this study

important to the overarching goal of the research to support women’s rights to decline recommended maternity care by promoting the need for systems-level responses to refusal.

Context and setting

This study was conducted in a large tertiary maternity service in Brisbane, Australia. This site was chosen because it had implemented a policy aiming to support women’s rights to refuse recommended maternity care through the MCP process. The MCP process was implemented in August 2010 to guide “communication and documentation [when] women … request maternity care contrary to hospital policy or guidelines” (Mater Health Services, 2010, p.1), that is, pregnant women who decline recommended care. The policy recognises the woman’s “absolute right to refuse any procedure” and describes the hospital’s “willingness to provide ongoing care”, including care which is “outside of hospital policy” (Mater Health Services, 2010, p.1-3).

Maternity Care Plans are used at the study site to document medically complex care (such as maternity care for women with cardiac conditions), as well as when women decline to follow professional advice. They are created only for women in the public maternity service (n=5,000 births approximately per year) where various models of care are available, including GP-shared care, hospital-based midwife/obstetrician antenatal clinics and midwifery group practices (which offer continuity of carer from booking to six weeks postnatally). There is no birth centre or publically funded homebirth at the study site.

The first step in initiating the study was to convene a steering committee involving myself, academic advisors, and obstetric and midwifery leaders at the study site. Partly this strategy was adopted to address Horner, Russ-Sellers and Youkey’s (2013, p. 1032) conclusion that effective HSR needs to be clinically driven, that is, that the “research questions … are articulated by patients, providers, or health systems themselves.” Involving study site obstetric and midwifery leaders from the earliest stages of the research, and seeking their input into the research design, not only secured access to the study site, but also helped to establish the study’s credibility with participants and underpinned their willingness to be interviewed. The involvement of the steering committee also contributed to the decision to begin with the collection and analysis of quantitative data; adhering to the methods most familiar to, and valued by, medicine was a pragmatic approach to the investigation of a sensitive topic. This high-level engagement underpinned the activist orientation of the research, making it more likely that recommendations would be considered for implementation.

Data collection

The collection and analysis of quantitative and qualitative data were guided by the research question under investigation and the methods most appropriate to the data (Brannen, 2004). These methods are summarised here and described in more detail in the relevant published papers (see Chapters Four, Five and Six).

Quantitative data

Maternity Care Plans

All MCPs created between August 2010 and December 2013 were extracted from a study site database, de-identified and reviewed by the steering committee to determine if their focus was on the care of a woman who had declined to follow professional advice. Maternity care plans which did have this focus were included; those with other foci (i.e. complex medical care) were excluded.

Chart audit

The charts of women with included MCPs were audited for:

- consent to be contacted about future research;
- need for translation services;
- notations about declining recommended maternity care.

Relevant annotations were de-identified and transcribed verbatim into a data collection spreadsheet (see Appendix A). For consistency, all of this data collection was completed by me, with a random selection of audited charts cross-checked by an academic advisor.

Clinical data

Routinely collected maternal and infant demographic and health outcomes data were extracted from MatriX, the study site’s electronic perinatal database. Outcome measures were derived from the Cochrane Protocol for review of models of maternity care (Hatem *et al.*, 2008). Selected de-identified health outcomes data were also extracted for all public hospital births at the study site during the study period to enable comparison between women with and without MCPs.

Qualitative data

Interviews with women, midwives and obstetricians

Interviews were sought with women who had MCPs, as well as with midwives and obstetricians who had provided maternity care to women in the context of an MCP. The inclusion of all three participant groups was critical to this study because they represent the three groups involved in hospital maternity care in Australia. The inclusion of women's voices (in this case both as service users and midwives) is also critical to feminist research (Hesse-Biber, 2010). The inclusion of highly empowered participants (obstetricians) was also important since studying elite groups has often been neglected in transformative research (Schneider & Aguiar, 2016).

Interviews were semi-structured[6] and followed feminist principles: Participants were invited to identify their preferred time and location for interviews, which were open-ended and directed by participants in order to build rapport and share power (DeVault & Gross, 2011; Oakley, 1981). Many of the principles of feminist interviewing are also consistent with approaches advocated for interviewing elite participants (Kezar, 2003), and therefore a similar approach was used in interviews with obstetricians also.

Where women had previously given their consent to be contacted about research, they were invited by letter to participate in an interview. I followed up with each invited woman (by telephone) one week later to seek her interest in participating in the study and answer any questions. Following this letter and phone call, no further contact was made with women unless they expressed interest in participating.

Obstetricians and midwives were invited to participate in the study via email from hospital managers and via information sessions, conducted by my advisors and me. A single follow-up email was sent one week later.

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[6] See also Appendix C: Interview Guide

Data analysis

Quantitative data

Content analysis of MCPs was undertaken using Microsoft Excel (see Appendix B). The analysis quantitised the textual data so that frequencies could be reported. It focused on the nature of the maternal refusal, the reasons for it, the care pathway documented, the gestation at which the MCP was created and the author. Demographic and health outcomes data for women with MCPs were entered into SPSS, de-identified, and analysed using simple descriptive statistics.

Routinely collected clinical outcomes data for all births during the study period were also used to identify cases where women had attempted vaginal birth after two caesareans (VBAC2) and more than two caesareans (VBAC>2) and breech vaginal birth. The vaginal birth rates amongst women with and without MCPs were then compared for women with at least two previous CS, and for women with breech presentations. Significance was determined using Fisher's exact test, which is suitable for small sample sizes (Lovric, 2011).

Qualitative data

Thematic analysis was undertaken using Braun and Clarke's six-step approach (see Figure 4) because it afforded theoretical flexibility and permitted insights across the spectrum of experiences amongst the diverse participant group (Braun & Clarke, 2006). Soon after each interview, I listened to the audio recording in full, making notes about ideas for analysis. I transcribed each recording verbatim and anonymised it. Data accuracy was supported by voice recording interviews and listening back to audio recordings after transcription to check for errors. Transcripts were not returned to participants for checking since the self-assessed accuracy of participant's views was not as important as the interpretations I ascribed to those views (Hagens *et al.*, 2009). The rigour of my interpretations was best upheld not by returning transcripts to participants, but by the process of inter-subjective checking described below.

Transcripts were uploaded to NVivo (QSR International, 2012) for analysis. I read each transcript in its entirety, and re-readings followed to identify comments related to the research questions. One of my advisors (SKr) and I jointly coded a selection of transcripts to create an initial coding scheme, which I used to code remaining transcripts, with adaptations made to accommodate new ideas. I worked iteratively, coding and grouping related comments into themes, which I tentatively labelled

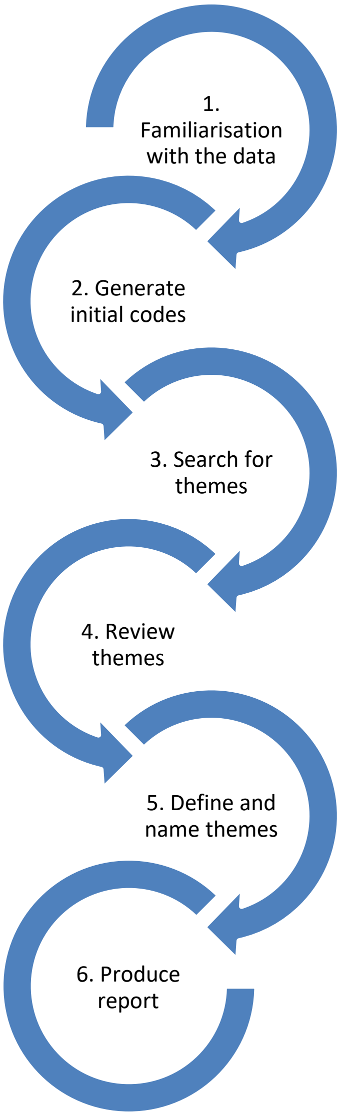

Figure 4: Six step approach to thematic analysis
(Source: Braun & Clarke, 2006)

and defined. My advisors and I independently reviewed data within each theme. Adaptations were made by consensus until stable themes were agreed by all.

In order to address this study’s goal informing change in maternity services, it was strategic to adapt Braun and Clarke’s approach by conducting two iterations of the qualitative analysis. In each iteration, the process described above was followed, but the two iterations differed in that the first took a more descriptive approach, while the second adopted a more critical feminist lens.

Descriptive thematic analysis

Stage one of the thematic analysis (the descriptive stage) focused on participants' views about the purpose of MCPs, the process of creating them, and their impact on subsequent maternity care (see Chapter Five). This stage of the analysis recognised that, although there was a more complex and power-laden story to be told, telling only that critical story would likely repel an obstetric audience. Obstetricians are the 'comfortable men' of maternity care (as discussed in Chapter One), and any change in that system depends on engaging them. However, that audience is unlikely to be engaged by research perceived as accusatorial or adversarial. It is to this idea that medical anthropologist Joralemon (2010, p. 100) referred when he concluded that "it is hard to 'afflict the comfortable' if they are not listening."

Feminist thematic analysis

This descriptive stage of the thematic analysis was not, however, intended to foreground the underlying values, attitudes and behaviours that influence the provision of maternity care in such situations. Rather, those insights were gained by extending the thematic analysis to include a more explicitly feminist lens and focussing on participants' broader comments about refusal of recommended maternity care (see Chapter Six). Adopting a feminist lens foregrounded issues of power and dominance, and enabled me to engage with the viewpoint of the most marginalised participant group, recognising that women's stories "were never mere anecdotes, but testimony through which the neglect and abuse of women by the health care system could be substantiated" and change wrought (Rich, 1995, p. xi).

Reflexivity

In feminist research, objectivity does not stem from the absence of bias, but from reflexivity. That is, by acknowledging and examining our own situated and contextualised relationship to the inquiry (Hesse-Biber, 2010). Reflexivity allows researchers to identify how personal values and assumptions have the potential to influence every stage of the research process (Finlay, 2002). Throughout the research process, I have explored my responses to the following questions, as suggested by Etherington (2004):

- How has my personal history led to an interest in this topic?
- What are my presuppositions about knowledge in this field?
- How am I positioned in relation to this knowledge?

- How does my subject-position influence my positioning in relation to this topic/the participants?

Throughout this study, I was mindful of how my own experiences led me to choose refusal of recommended maternity care as the focus of my research and the need to locate myself within the research. By maintaining reflexivity, I strived to highlight my own values and assumptions, and locate myself (and my premise that accommodating women's birth intentions is integral to respectful maternity care), at the centre of this research. A transparent account of my values and assumptions enables readers to judge the credibility of the study.

I chose to birth my three children at home with the care of privately practising midwives because I perceived that that model of care would afford me the greatest degree of autonomy to pursue the low-interventions births that I hoped for. I wanted to avoid hospital maternity care because I perceived that the medicalised model which dominates in Australian hospitals (as discussed in Chapter 1) would make it difficult for me to resist unnecessary intervention. For example, while I may have initially been able to access birth centre care (subject to a lottery system due to the model of care being over-subscribed), because I declined routine ultrasounds, I would not have been 'allowed' to continue in that model of care.

Although I initially perceived that my choice to birth at home was a personal one (not a political one), soon after my second child was born, changes in the regulation of health care professions in Australian threatened to make it illegal for midwives to attend births at home. I became an active member of Maternity Coalition (MC; now, Maternity Choices Australia), Australia's national maternity consumer[7] organisation. My work with MC involved consumer representation on State and National committees, political activism, and advocacy for individual women. This volunteer work sensitised me to some of the barriers to woman-centred care and in particular, to the constraints on women's birth choices. I formed the view that although requesting intervention (such as pharmacological pain relief or caesarean section) may be a similar and equally legitimate

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[7] 'Consumer' is an accepted term in Australia, regarded as more appropriate and empowering to pregnant and birthing women than referring to them as 'patients'. The analogous term 'service user' is common in other settings. Nonetheless, I acknowledge that 'consumer' is not an unproblematic label: It is too easily co-opted by a neoliberalist agenda and "confines pregnant women and mothers to recipients of maternity services rather than agents and policy shapers and makers" (Daellenbach & Edwards, 2010, p. 225).

exercise in autonomy (Hellmark Lindgren, 2006), at least in Australia, there appeared to be fewer barriers to women requesting intervention than declining it.

My own birth choices attest both to the value I placed on personal autonomy and to my perception that I would have the most autonomy in a private midwifery model of care. That presupposition was strengthened during my volunteer work with MC. It is also a view that is widely shared in the homebirth community, and which in my view, deters some women from hospital birth, even if they develop risk factors that may make hospital birth safer for them, at least in the biomedical sense. I, therefore, came to this study with the belief that strategies to better support women's rights to decline recommended maternity care in hospital settings were both needed and important for the safety (not just in the biomedical sense) of women and their babies.

Ethical considerations

Ethics approval for the study was obtained from both the hospital and university ethics review committees (approval numbers: HREC/13/MHS/31, and 2013001320 respectively). The following sub-sections describe the major ethical considerations in the conduct of this study.

Informed consent

Interview participants were provided with a Participant Information and Consent Form. Prior to the commencement of interviews, I confirmed that the participant had read and understood the PICF, answered any outstanding queries, and sought their written consent to participate.

In all communication with participants, they were made aware that they were free to withdraw without penalty from the study at any time until their data was de-identified and analysed.

Confidentiality

All raw data were anonymised, and pseudonyms have been used in all reporting.

All data were password protected and stored on the Mater Research Institute network (backed up daily) or in a locked cabinet, accessible only to my advisors and me. At the conclusion of the project, all data were securely archived at the Mater Research Institute.

Potential risks and benefits of the project

I was prepared for the possibility that participants may become upset during interviews. In that event, data collection ceased, and the participant was offered a break from the interview, with the option of proceeding then, later or not at all. All participants were made aware of the availability of counselling services at the study site in case they wished to discuss their experiences further, but funding to access these services was not offered.

Conclusion

This chapter has described the methodology and methods used in this study. A feminist approach to HSR has been justified, and the sequential explanatory mixed methods design (participant selection model) described. I have outlined the importance of reflexivity in this study and highlighted my own situated and contextualised relationship to the inquiry. The principal ethical considerations inherent in the conduct of this study have also been outlined. The following chapters present the findings of this study in the form of published papers. Each paper is prefaced by a brief orientation that outlines the significance of that paper and its place within the overall study. Each paper describes the specific data collection and analysis methods used, and so these aspects of this chapter are revisited and developed further in the relevant chapters.

Chapter Four: Getting the comfortable to listen: working with decision makers to enable change

Orientation

As outlined in Chapter Two, clinicians experience ethical and moral turmoil and practice in the context of limited and ambiguous guidance when caring for women who decline to follow advice. This situation has persisted despite numerous studies which have called for greater support, and growing attention on over-medicalisation, disrespect and abuse in maternity care as human rights issues. Processes to discuss and document refusal with women have been theorised in the literature, but not systematically studied in clinical practice. Chapter Three described a feminist approach to mixed methods health services research which guided the current study towards its overall aim of promoting the need for systems-level responses to refusal of recommended care.

Respected epidemiologist and perinatologist Marsden Wagner, once used the adage “a fish can’t see water” to explain why the problems of medicalised maternity care are largely invisible to many of the clinicians immersed in it (Wagner, 2001, p. s25). Likewise, Diaz-Tello (2016a) argues that the problems of disrespect and abuse in maternity care are widely denied in medical circles. Such denials, part of the privilege enjoyed by Murphy-Black’s (1995) comfortable men[8] of maternity care, could easily see this study alienate or be dismissed by the very clinicians it sought to influence. Joralemon (2010, p. 100) argues then that it is only by getting the comfortable to listen that we can hope to influence them. A strategic approach was therefore needed to engage doctors and health service managers.

This chapter represents the first step in that strategic approach: getting the comfortable men of maternity care to listen to the issue of respect for women’s autonomy. It does this by attending to the first objective of this study, which was to review the processes and outcomes associated with a structured documentation and communication process used in one tertiary hospital when women declined recommended maternity care. This meant that the study began with the production of quantitative data that doctors and health service policy makers were most likely to value and perceive as ‘objective.’ These data were also essential to the selection of participants for the subsequent in-depth semi-structured interviews (see Chapters Five and Six).

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[8] A discussed in Chapter One, the concept of ‘comfortable men’ refers not just to males or obstetricians, but to all those (regardless of gender or profession) who have been enculturated into contemporary medicalised maternity care.

The retrospective review reported in this chapter is the first study to examine, in practice, the use of a structured process for communicating about and documenting refusal of recommended care. It was developed as a paper for publication, and is included in its entirety in this chapter. It was published in 2015 in *Women and Birth*, which is a leading, international, peer-reviewed midwifery journal, currently ranked eighth of 116 journals in the field.

Maternity Care Plans: A retrospective cohort study of women who declined standard maternity care.

Abstract

Background

All competent adults have the right to refuse medical treatment. When pregnant women do so, ethical and medico-legal concerns arise and women may face difficulties accessing care. Policies guiding the provision of maternity care in these circumstances are rare and unstudied. One tertiary hospital in Australia has a process for clinicians to plan non-standard maternity care via a Maternity Care Plan (MCP).

Aim

To review processes and outcomes associated with MCPs from the first three and a half years of the policy's implementation.

Methods

Retrospective cohort study comprising chart audit, review of demographic data and clinical outcomes, and content analysis of MCPs.

Findings

MCPs ($n = 52$) were most commonly created when women declined recommended caesareans, preferring vaginal birth after two caesareans (VBAC2, $n = 23$; 44.2%) or vaginal breech birth ($n = 7$, 13.5%) or when women declined continuous intrapartum monitoring for vaginal birth after one caesarean ($n = 8$, 15.4%). Intrapartum care deviated from MCPs in 50% of cases, due to new or worsening clinical indications or changed maternal preferences. Clinical outcomes were reassuring. Most VBAC2 or VBAC>2 (69%) and vaginal breech births (96.3%) were attempted without MCPs, but women with MCPs appeared more likely to birth vaginally (VBAC2 success rate 66.7% with MCP, 17.5% without; vaginal breech birth success rate, 50% with MCP, 32.5% without).

Conclusions

MCPs enabled clinicians to provide care outside of hospital policies but were utilised for a narrow range of situations, with significant variation in their application. Further research is needed to understand the experiences of women and clinicians.

Keywords

Hospitals, maternity; Policy; treatment refusal; refusal to treat

Background

Pregnant women, like all competent adults, have the right to refuse medical treatment. Autonomy, choice and informed consent underpin healthcare policy generally, and maternity specifically (Commonwealth of Australia, 2009; Department of Health, 1993). When pregnant women decline recommended care, concerns about maternal and fetal safety can lead to conflict. Clinicians may also feel their own autonomy is challenged or that the care preferred by the woman is beyond their expertise (Brazier, 2006). Ethical turmoil and medico-legal concerns for clinicians are well documented (Hall *et al.*, 2012; Kruske *et al.*, 2013), and in some cases, women face difficulties accessing the care they prefer (Charles, 2012).

Women who decline recommended maternity care may have poorer perinatal outcomes (Iris *et al.*, 2009; Ribak *et al.*, 2011) and debate continues over the nature of a pregnant woman's obligations to her fetus (Savulescu, 2007; Scott, 2000). However, there are few, if any, circumstances under which any such obligations could override a competent woman's right to refuse medical treatment (Berkowitz, 2004; Burrows, 2001).

Professional guidance for midwives and obstetricians emphasise the importance of informed consent and respect for patient autonomy (Australian College of Midwives (ACM), 2014; Australian Medical Association (AMA), 2013; FIGO Committee for the Study of Ethical Aspects of Human Reproduction and Women's Health, 2012; Royal Australian and New Zealand College of Obstetricians and Gynaecologists (RANZCOG), 2006b). Although clinicians' rights to withdraw care are protected in all but emergency situations (ACM, 2014; AMA, 2013; FIGO, 2012; RANZCOG, 2006b), doing so may undermine women's autonomy (Scott, 2010). Processes to guide clinicians who continue to provide maternity care after women have declined recommended care are rare and unstudied. Cuttini and colleagues found that such situations present an unresolved "ethical conflict" (Cuttini *et al.*, 2006, p.1121).

Evidence-based clinical guidelines are increasingly used to standardise practice (Willis, 2006) and whilst adherence may reduce medico-legal risk (Ransom *et al.*, 2003), it may also restrict women's and clinicians' autonomy (Parker, 2005; Scamell, 2014). One study (van der Weijden *et al.*, 2013) examined how guidelines can be adapted to more directly support shared decision-making, however, there is a dearth of literature exploring strategies to support clinicians and women in situations where recommended care is declined. The World Health Organisation has similarly called for research related to respectful maternity care practices (WHO, 2014).

Most of the published literature concerning women who decline recommended care focusses on the experiences of clinicians (Chigbu *et al.*, 2009; Cuttini *et al.*, 2006; Danerek *et al.*, 2011) and their attitudes to court intervention (Samuels *et al.*, 2007); the experiences of women are less commonly described. Three papers (Chervenak & McCullough, 1990; Deshpande & Oxford, 2012; Pinkerton & Finnerty, 1996) have described processes for managing a broader range of situations in which women may decline recommended care, although none reports on the efficacy of those processes in clinical practice.

A large tertiary hospital in Brisbane, Australia, developed a process to enable clinicians to provide care for women who declined standard care. The Maternity Care Plan (MCP) policy was implemented in August 2010 to guide “communication and documentation [when] women … request maternity care contrary to hospital policy or guidelines,” (Mater Health Services, 2010, p.1) that is, women who decline standard care. The policy directs that a consultant obstetrician meet with such women during the antenatal period to discuss and document their intentions in an MCP, ensuring that the woman receives information about the “risks and benefits of all options, including the option to have no treatment [and] a clear, evidence-based and rational response … as to why standard care would be advised” (Mater Health Services, 2010, p.1). When women decline standard care during labour, the policy indicates that the process of obstetric consultation should be followed and documented in the woman’s health record, but without the creation of a discrete MCP. The policy recognises the woman’s “absolute right to refuse any procedure” and describes the hospital’s “willingness to provide ongoing care,” including care which is “outside of hospital policy” (Mater Health Services, 2010, p.1-3). Figure 5 describes the MCP process.

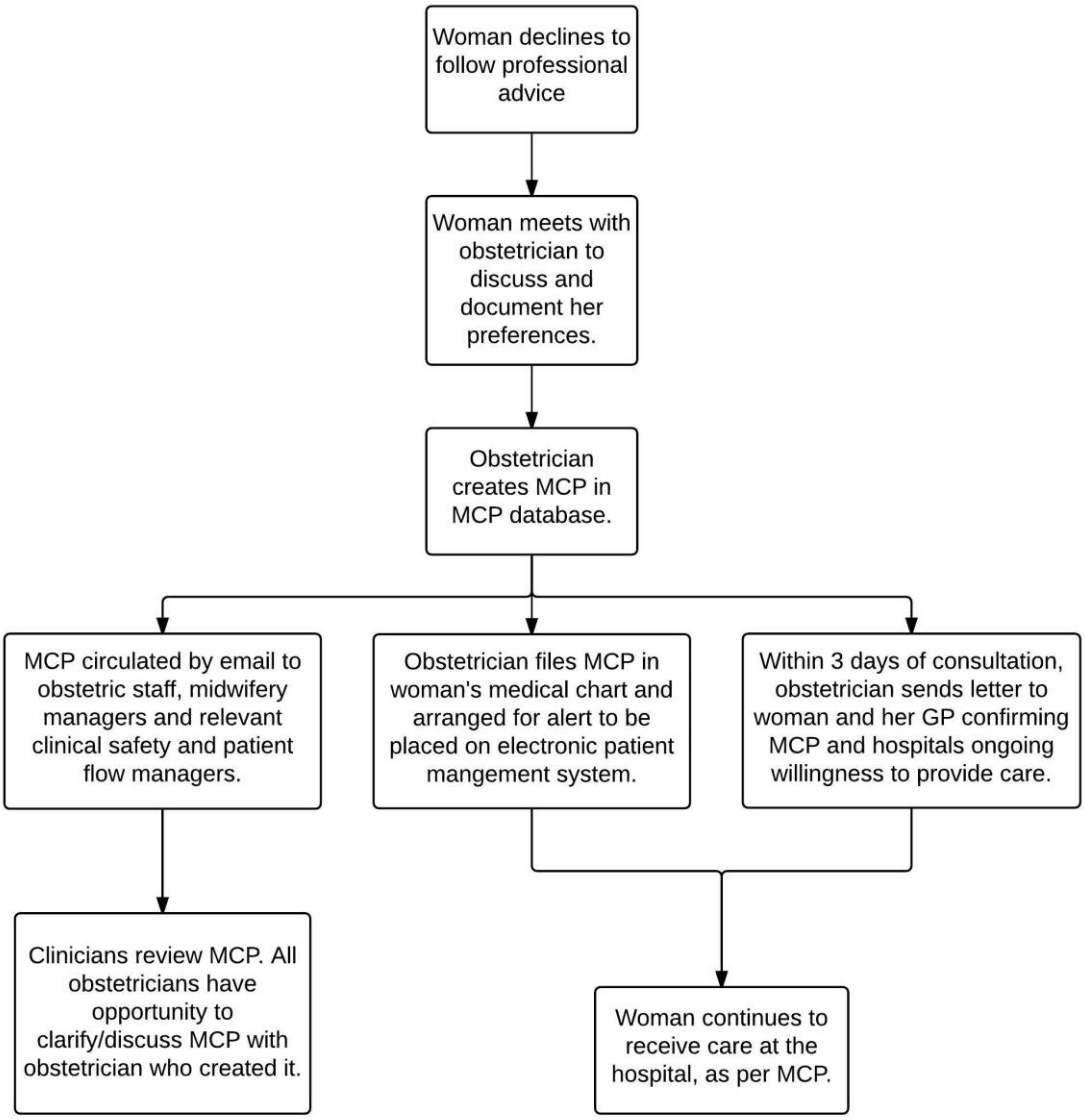


Figure 5: The MCP Process

Methods

Aim and objectives

The study aimed to review the processes and outcomes associated with MCPs created for women who declined standard maternity care, during the three and a half years following the introduction of the MCP policy (August 2010-December 2013). The objectives included:

- To undertake a content analysis of MCPs;
- To describe relevant demographic details and clinical maternal and infant outcomes of women with MCPs;

- To compare relevant clinical outcomes to the whole public maternity hospital population over the same time period;
- To undertake a chart audit to determine and classify reasons for any differences between planned care described in the MCP and actual intrapartum care.

Design

A retrospective cohort study. Approval was obtained from both hospital and university ethics committees.

Research setting

Australia has a system of universal public healthcare provision, as well as a parallel private healthcare system. The study was conducted at a large tertiary maternity service in Brisbane, Australia, which has co-located public and private maternity services. MCPs were only created for women in the public sector. Approximately 10,000 women per year birth at the study site, over half of whom are public patients (Mater Health Services, 2014).

Data collection

All MCPs created during the study period were extracted from the hospital database and exported to an MS Excel spreadsheet. Because MCPs are also created for pregnant women with complex medical needs (such as cardiac conditions), each MCP was reviewed to decide its inclusion. All MCPs focused on non-standard maternity care, and where the woman had already birthed, were included.

Routinely collected demographic and maternal and infant clinical data for all women with an included MCP were extracted from MatriX (Meridian Health Informatics, NSW, Australia), the information system used at the study site. MatriX and MCP data sets were merged and de-identified, creating a single research database in SPSS (Version 18.0.3).

The charts of women with MCPs were audited for antenatal and intrapartum progress notes related to their MCP. Relevant annotations in charts were copied verbatim into a data collection spreadsheet, then merged into the research database.

Selected clinical outcomes for all public sector births at the study hospital during the study period were also extracted from Matrix and organised in a de-identified SPSS database.

Data analysis

Content analysis of MCP data identified the gestation at which the MCP was created, the author (coded) and categorised the type of non-standard care.

Simple descriptive statistics described the population of women with MCPs and their intrapartum outcomes. These outcomes were then matched to the planned outcomes described in the woman's MCP. The chart audit examined if and when planned care changed (i.e. prior to, or during labour), classified documented reasons for variations from the MCP.

Comparisons were made between selected variables for women with MCPs and the wider hospital maternity population. Since it was possible to identify women who attempted vaginal birth after caesarean sections (VBAC) and vaginal breech birth in the public maternity population, success rates for both cohorts of women (i.e. with and without MCPs) were compared.

Results

The hospital database contained 135 MCPs created during the study period, of which 52 were related to non-standard maternity care and were included. The remaining 83 MCPs were excluded as they related to complex medical care.

Table 1 demonstrates that most women with MCPs were multiparous (*n*=46, 88.5%) and socio-economically advantaged (SEIFA quintiles 4 and 5, *n*=24; 70.6%). Although most women with MCPs were Caucasian (*n*=35, 72.9%), women of African ethnicities were more common in the MCP cohort than in the wider hospital population where approximately 2.3% of women are of African ethnicities (Mater Health Services, 2009). Five women had been refused care elsewhere because of their birth preferences; four from a nearby public hospital and one from a private obstetrician. Of these women, four were planning vaginal births after two caesareans (VBAC2), and one had declined continuous fetal heart monitoring for a planned vaginal birth after one previous caesarean section (VBAC1). Three women did not birth at the study site following the creation of their MCP.

Table 1: Characteristics of women with MCPs related to non-standard care. (n=52)

Maternal Characteristics		n	%
Age	20-24	1	1.9
	25-29	15	28.8
	30-34	19	36.5
	35-39	13	25
	40+	4	7.7
SEIFA quintile[*]	SEIFA 1	4	11.8
	SEIFA 2	1	2.9
	SEIFA 3	5	14.7
	SEIFA 4	11	32.4
	SEIFA 5	13	38.2
Ethnicity[#]	Caucasian	35	72.9
	Indigenous	2	4.2
	Asian	3	6.3
	African	8	16.7
Parity	Multiparous	46	88.5
Plurality	Twins	1	2.9
Gestation at creation of MCP	<37weeks+0 days	14	26.9
	37-40 weeks	31	59.6
	Post 40 weeks	7	13.5

* Socio-Economic Indexes for Areas (SEIFA), where the first quintile is the least advantaged and the fifth quintile is the most advantaged. Missing SEIFA score data, n=18.

[#] Missing Ethnicity data, n=4.

MCPs (n=52, Figure 6) were most commonly created when women declined recommended caesarean sections (CS), preferring VBAC2 (n=23; 44.2%) or vaginal breech birth (n=7, 13.5%) or when women declined routine intrapartum monitoring for VBAC1 (n=8, 15.4%). VBAC2 and VBAC>2 MCPs were prompted by the number of previous CS a woman had experienced and documented her intention to accept routine intrapartum monitoring. Documentation indicated that nine women (17.3%; all VBACs) had been given additional written information (pertaining to the risks of VBAC) by midwives or obstetricians during their antenatal care. Most MCPs (*n*=38, 73.1%) were created after 37 weeks gestation, most commonly at 39 (*n*=10, 19.2%) or 40 weeks (*n*=10, 19.2%), however, midwives had often recorded the woman's preferences as early as the booking visit. Seven charts (13.5%) also contained birth plans written by women.

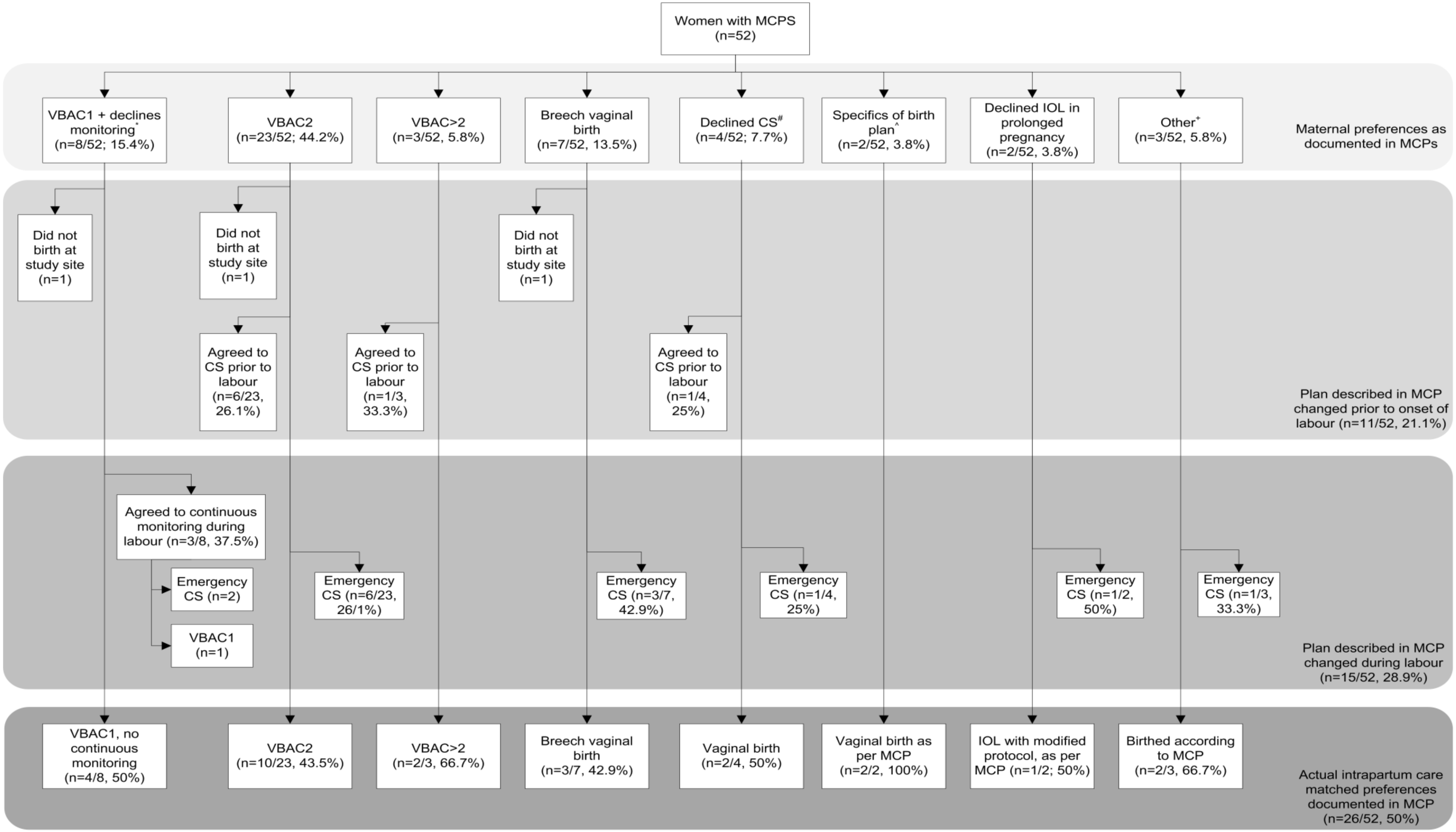
Authorship of MCPs was not uniformly distributed amongst obstetricians, with one individual creating almost twice as many MCPs as the next most frequent author (*n*=11, compared with *n*=6). Most obstetricians created a maximum of three MCPs during the study period and some may have been absent from the database having not authored any. In most MCPs (*n*=37, 71.2%) there was no record of consultation with other clinicians. Where consultation was documented, it was with other obstetricians (*n*=12, 23.1%), other doctors such as anaesthetists (*n*=8, 15.4%) or midwives (*n*=6, 11.2%).

Actual care compared to planned care

Figure 6 describes the actual care received by women with MCPs. Women's intrapartum care followed the preferences documented in their MCPs in 50% of cases. Neither ethnicity nor SEIFA score was significantly associated with the probability that a woman would achieve her intended birth.

For 11 women (21.1%), the plan described in their MCP changed prior to the onset of labour. Three women (5.8%) did not to seek further maternity care at the study site; one birthed at home, one in another hospital and one was lost to follow-up. Eight women whose MCPs documented that they preferred vaginal birth, underwent CS prior to labour either because of new or worsening clinical indications (such as chorioamnionitis or pre-eclampsia), or because the woman did not go into labour at, or soon after, her due date or because she changed her mind.

For 15 (28.8%) women the plan described in their MCPs altered during intrapartum care. Three women whose MCPs documented that they had declined routine intrapartum monitoring during VBAC1s, accepted continuous fetal heart monitoring during labour after intermittent auscultation indicated concern. Two then had emergency CS; the third birthed vaginally. Six women whose MCPs related to planned VBAC2 had emergency CS because of concern for fetal well-being (based on fetal heart rate monitoring and/or fetal scalp lactate) or because they did not establish or progress in labour.



* Included MCPs documenting planned VBAC1 where woman declined routine continuous electronic fetal heart monitoring;
# women who declined CS recommended for medical reasons, such as maternal cardiac conditions.
^ MCPs documented a suite of maternal preferences including: declining routine intrapartum monitoring, phsyiological third stage of labour and restricting the number of clinicians in the room;
\+ Women who requested certain interventions including CS and induction of labour (IOL).

Figure 6: Actual care of women with MCPs

Six women commenced labour with MCPs that indicated a preference for vaginal breech birth; three had emergency CS, two due to unfavourable breech presentations identified in early labour and one when her labour did not progress. One woman whose MCP documented her preference not to be induced went into spontaneous labour after 42 weeks gestation but consented to an emergency CS due to slow progress.

In total, 15 emergency CS were performed; one prior to labour, 14 during labour. Two were recorded as being category one (both in the context of VBA2Cs), indicating an immediate threat to the life of the woman or fetus (RANZCOG, 2006a).

Table 2: Clinical outcomes of women with MCPs and their babies (*n*=49)[1]

Maternal Characteristics	n	%
Maternal Length of Stay (days)[2]		
Less than 1 day	2	4.4%
1-2 days	28	62.2%
2+ days	15	33.4%
Neonatal outcome		
Liveborn, survived	48	98.0%
Liveborn, neonatal death	1	2.0%
Apgar <7 at 5 mins[3]		
Yes	2	4.0%
Neonatal nursery admissions		
Special Care Nursery	5	10.0%
Neonatal Intensive Care	2	4.0%

1. Excluded women (*n*=3) who had MCPs but did not birth at the study site.
2. Missing data, *n*=4
3. Missing data, *n*=1.

Clinical outcomes for women with MCPs

Clinical outcomes were analysed for the 49 women who birthed at the study site (see Table 2). There were no maternal deaths, and all babies were liveborn. The single neonatal death was due to a previously diagnosed lethal congenital anomaly. Recovery from CS (*n*=12, 80%) accounted for the majority of women hospitalised beyond two days (*n*=15). Seven babies were admitted to neonatal nurseries due to prematurity (*n*=3), known congenital anomalies (*n*=2), following resuscitation (*n*=1) or with low birth weight (*n*=1).

Clinical outcomes for women with and without MCPs

The prevalence of MCPs for VBAC2, VBAC>2, and vaginal breech birth was examined in the context of all public births for women with these presentations (*n*=18,238). For the cohort of women without MCPs, we defined 'attempting' a VBAC2, VBAC>2 or vaginal breech birth as having commenced labour, at or after 37 weeks gestation, with the relevant obstetric history. Fifty-eight women attempted VBACs after at least two prior CS and vaginal breech births were attempted by 160 women. Women with MCPs constituted 31% (*n*=18/58) of the VBAC2/VBAC>2, and 3.8% (*n*=6/160) of the vaginal breech birth groups. Amongst the women who attempted a VBAC2 or VBAC>2, 66.7% (*n*=12/18) of those with MCPs had a vaginal birth, compared to 17.5% (*n*=7/40) of those without. Amongst the women who attempted a vaginal breech birth, 50% (*n*=3/6) of those with MCPs had a vaginal birth, compared to 32.5% (*n*=50/154) of those without.

Discussion

This paper aimed to describe the implementation and early use of MCPs in a large tertiary maternity hospital. Although many maternal choices may be considered controversial (Little *et al.*, 2008), MCPs provided a process for obstetricians to discuss and document the woman's intentions, and then for all clinicians subsequently involved to provide care which fell outside of hospital policies. In this way, women were neither compelled to adhere to hospital policies nor refused care. This is an important and encouraging finding since Berwick describes rigid policy-driven practice as the antithesis of patient-centred care (Berwick, 2009). In half of the MCP cases (*n*=26, 50%), women's intrapartum care matched the preferences documented in their MCPs. Of the remaining 26 women, 23 accepted interventions they had previously declined, usually in the context of new clinical indications; three women chose not to birth at the study site. Clinical outcomes were reassuring, with no adverse events attributable to women having declined standard care. This suggests that the MCP process enabled women to access care that was contrary to hospital policies, but which remained responsive to new clinical indications. In this way, the MCP process appeared to support the woman's autonomy without compromising safety for her or her baby.

In five cases, MCPs were used to accommodate the care preferences of women who had been refused care elsewhere. When women's choices are constrained by lack of access to care, their autonomy is undermined and, in this respect, limited access to VBAC and vaginal breech birth is a growing threat to women's autonomy and to the quality of maternity care (Charles, 2012).

The MCPs were used infrequently with only 52 (2.85 per 1000 births) created during the study period. The rarity of MCPs may not reflect the frequency with which women would prefer non-standard care, but rather that MCPs were used to document a narrow range of planned intrapartum care, mostly related to VBAC and vaginal breech birth. Strategies may be needed to increase both clinician's and women's awareness of decision points throughout the maternity care episode. Other studies (Kotaska, 2007; Thompson & Miller, 2014) have found that clinicians regarded certain obstetric procedures (such as epidurals) as more discretionary than others and that women were more likely to be informed and involved in decision-making on those procedures, than on procedures regarded as routine (such as amniotomy or vaginal examinations). It was not possible in this study to discern whether maternal preferences which related to other aspects of standard care were accommodated without an MCP, or the extent of involvement in decision making afforded to women who did not receive an MCP, but who may have wanted non-standard care.

There appeared to be inconsistencies in the application of the MCP policy. The majority of VBAC2/VBAC>2 (69%) and vaginal breech births (96.2%) were managed without an MCP. Local policies (Mater Health Services, 2012a, 2012b) at the study site support both VBAC2 and vaginal breech birth (in the absence of contraindications), suggesting that these situations may not always constitute non-standard care nor warrant an MCP. The local VBAC policy (Mater Health Services, 2012a, p. 1) describes "more than two previous caesareans" as a contraindication, and although this policy was implemented part way through the study period, MCPs continued to be created for VBAC2. In each VBAC2 case, neither the chart review nor content analysis revealed contraindications that would account for the use of the MCP. The breech vaginal birth policy (Mater Health Services, 2012b) is ambiguous calling for MCPs even when planned breech vaginal birth is not contraindicated, possibly creating confusion about the role of MCPs.

Obstetricians may not create an MCP when they feel comfortable providing obstetric support for women requesting non-standard care. However, particularly in fragmented models of care, varying comfort levels between obstetricians and clinical scenarios may lead to women receiving conflicting advice, and subsequently to patient distrust (Browner & Press, 1996). The large number of MCPs created by one author also suggests uptake of MCPs is variable. Further investigation of clinician's experiences of the MCP process, currently being undertaken, may explain this variation.

The apparently higher VBAC2/VBAC>2 and vaginal breech birth success rates amongst women with MCPs is encouraging and worthy of further investigation. We acknowledge that women with MCPs may have been more determined and willing to accept a degree of risk in pursuit of their preferred labour and birth, but it may also be that MCPs enabled them to receive more supportive care. Also, we acknowledge that these results should be interpreted with caution, given the small sample size, possible presence of confounders and because the definition of attempted a vaginal birth may have over included women without MCPs. Further research is currently being undertaken to explore women's and clinicians' experiences of the MCP process to better understand how it functions in practice and to account for the apparently higher VBA2C and vaginal breech birth success rate amongst women with MCPs.

Although we were unable to locate literature which discussed processes akin to MCPs, studies examining birth plans written by women to communicate birth preferences to clinicians may provide a basis for comparison. The potential for MCPs to positively impact women's birth outcomes is at odds with the findings of studies which concluded that birth plans did not benefit women (White-Corey, 2013) or that they may undermine supportive care (Lothian, 2006). Compared to birth plans, the credibility of MCPs is likely to be rated more highly because they are written exclusively by obstetricians. This may have helped to diffuse the tension which Lothian (2006) suggested birth plans can provoke. Although birth plans may be consistent with standard maternity care options, women may nonetheless benefit from more systematic efforts to elicit their preferences and, where appropriate, initiate an MCP. Without such efforts, women who would prefer non-standard care may not disclose their wishes, perhaps in order to avoid perceived criticism or out of concerns that they would be required to consent to standard care. Other studies have reported women avoiding scrutiny by disengaging with care (Ireland *et al.*, 2011; Kornelsen & Grzybowski, 2012).

The late gestation at which most MCPs were created deserves further examination. Chart audit revealed that many women had mentioned their preferences for non-standard care (especially for VBACs) at booking in with a midwife, but most MCPs were not created until after 37 weeks, by an obstetrician. Delaying the creation of MCPs may save resources (time) by minimising the frequency with which they are discarded or superseded as clinical indications or maternal preferences change. However, the delay may also undermine women's autonomy as the literature suggests that women fear hostility and withdrawal of care late in pregnancy, as the later in pregnancy the greater the power disparities between them and clinicians (Cherniak & Fisher, 2008). Increasing the involvement of midwives in the MCP process may facilitate earlier initiation and ongoing discussion of the woman’s options because women most frequently see midwives during their antenatal care at the study site. Also, most women in Australia see their General Practitioner (GP) for pregnancy confirmation, and approximately 21% continue with GP shared care throughout their pregnancy (Australian Health Ministers' Conference, 2010). Given the prevalence of this model of care, it would also seem useful to ensure that GPs are similarly aware of, able to inform women about and initiate the MCP process.

Implications for practice and policy

A formal documentation and communication process, such as the MCP, can support both clinicians providing non-standard maternity care and women attempting their preferred birth as safely as possible. However, these findings also highlight opportunities to refine the process.

Consensus is needed about which situations warrant an MCP. Although most VBA2C and vaginal breech birth attempts occurred without an MCP, consistent practice is desirable. The burden of additional documentation should be reserved for clinical scenarios for which local policies do not exist or where there are known contraindications. However, the narrow range of clinical scenarios documented suggested that MCPs may be underutilised as examples of routinely performed interventions, which some women may prefer to decline, were not identified. Systematic clinician-led efforts to elicit women’s preferences and more consistent identification of situations which warrant an MCP may increase women’s involvement in decision-making. Given the routine nature of many aspects of pregnancy care, we suggest that strategies which highlight decision points to women and clinicians could be introduced. We suggest that women should also receive a copy of their MCP. Wäckerle and colleagues (2010) found that providing such records to pregnant women contributed positively to patient empowerment, satisfaction and safety.

The MCP process could be further strengthened by careful consideration of the most appropriate gestation to create an MCP. Initiating the process when the woman mentions her preferences (even when that is early in pregnancy) may better meet women’s needs. Given that early antenatal care is often with midwives and GPs, these clinicians should be able to inform women about, and initiate, the MCP process.

Limitations of this study

Although this study included all MCPs related to non-standard maternity care, the sample size was small, precluding conclusions about rare clinical outcomes. Also, MCPs were not used for women who refused blood products (covered by a separate local policy) or when they declined care recommended during labour. It was also not possible in this study to discern whether MCPs accurately reflected women's preferences.

Analysis of the frequency of VBAC2, VBAC>2 and vaginal breech birth in the whole public maternity hospital population was limited by our definition of 'attempted this outcome.' It was beyond the scope of this study to discern the intended mode of birth amongst women without MCPs.

This study also did not report on the organisational culture in which the MCP policy was developed and utilised, although we acknowledge that this is likely to impact on its effectiveness and appropriateness.

Finally, although MCPs appear to have enabled some women to decline standard care, this paper has not examined the extent to which the process meets the needs of women or clinicians.

Conclusion

This study has described the nature and documentation of maternity care, both planned and actual, provided to women who declined standard care following the implementation of the MCP policy. Results suggest that it enabled women to decline aspects of standard care and clinicians to provide care that did not adhere to hospital policies. However, MCPs were utilised for a narrow range of clinical scenarios. Significant variation in the use of the MCP process has been highlighted. Further research is underway to examine women's and clinician's experiences of non-standard maternity care, as well as exploring apparent differences in VBAC and vaginal breech success rates amongst women with and without MCPs.

Chapter Five: The usefulness (or not) of a structured process for documentation and communication when women decline recommended care

Orientation

Chapter Four presented the findings of a retrospective review of cases of where women were documented to have declined recommended care in one tertiary hospital. That review found that the Maternity Care Plan (MCP) process had enabled women to decline aspects of recommended care and enabled clinicians to provide care that did not adhere to hospital policies. However, the process was used rarely, only in a narrow range of clinical scenarios, and with significant variation in its application.

To explain and expand upon the quantitative phase of the study, in-depth semi-structured interviews were undertaken with women, midwives and obstetricians who had been involved in the MCP process at the study site. The literature on this topic has been dominated by surveys of obstetricians' views about the use of court intervention to authorise treatment on non-consenting women. This study looked beyond such overt coercion since it is almost unheard of in Australia and widely condemned internationally. Also, in-depth, semi-structured interviews enabled the exploration of participants' experiences in a more open-ended way. The inclusion of women and midwives was significant because these voices (particularly women's) are been largely absent from the literature. Finally, although documentation and communication processes to support clinicians' have been theorised in the literature, this study is the first to examine the usefulness of such a process in practice.

As described in Chapter Three, the analysis of interview data was undertaken in two stages, one descriptive and one feminist. This chapter presents the descriptive stage of that analysis, which focused on participants' views about the purpose of MCPs, the process of creating them, and their impact on subsequent maternity care. Although there was also a more complex and power-laden story to be told (which is taken up in Chapter Six), this descriptive stage of analysis served the important function of engaging maternity care providers who may have rejected a more critical analysis if it was perceived to (only) criticise them. Furthermore, the transformative approach adopted calls upon researchers to "develop strategies to determine different versions of reality" (Mertens, 2012, p. 808). My layered approach to the thematic analysis is one such strategy, with this chapter foregrounding clinicians' realities.

The descriptive thematic analysis was developed as a paper for publication, which is reproduced in this chapter. The paper, the second arising from this thesis, was made 'Editor's Choice' following its publication in *Women and Birth* in 2016.

Women's, midwives' and obstetricians' experiences of a structured process to document refusal of recommended maternity care.

Abstract

Background

Ethical and professional guidance for midwives and obstetricians emphasises informed consent and respect for patient autonomy; the right to refuse care is well established. However, the existing literature is largely silent on the appropriate clinical responses when pregnant women refuse recommended care, and accounts of disrespectful interactions and conflict are numerous. Policies and processes to support women and maternity care providers are rare and unstudied.

Aim

To document the perspectives of women, midwives and obstetricians following the introduction of a structured process (Maternity Care Plan; MCP) to document refusal of recommended maternity care in a large tertiary maternity unit.

Methods

A qualitative, interpretive study involved thematic analysis of in-depth semi-structured interviews with women (n=9), midwives (n=12) and obstetricians (n=9).

Findings

Four major themes were identified including: 'Reassuring and supporting clinicians'; 'Keeping the door open'; 'Varied awareness, criteria and use of the MCP process' and 'No guarantees.'

Conclusion

Clinicians felt protected and reassured by the structured documentation and communication process and valued keeping women engaged in hospital care. This, in turn, protected women's access to maternity care. However, the process could not guarantee favourable responses from other clinicians subsequently involved in the woman's care. Ongoing discussions of risk, perceived by women and some midwives to be pressure to consent to recommended care, were still evident. These limitations may have been attributable to the absence of agreed criteria for initiating the MCP process and fragmented care. Varying awareness and use of the process also diminished women's access to it.

Keywords

hospitals, maternity; policy; treatment refusal; personal autonomy; refusal to treat; professional autonomy.

Background

A competent adult's right to refuse recommended care is well established (McLean, 2009) and ethical and professional guidance for midwives and obstetricians emphasises informed consent and respect for patient autonomy (Australian College of Midwives (ACM), 2014; FIGO Committee for the Study of Ethical Aspects of Human Reproduction and Women's Health, 2012; Royal Australian and New Zealand College of Obstetricians and Gynaecologists (RANZCOG), 2006b). Simultaneously, however, there is growing emphasis on the use of evidence-based clinical guidelines to standardise practice (Kotaska, 2011a). While this has been useful in displacing practices based only on tradition and anecdote, what counts as 'evidence' is mediated by a culture that favours technology and intervention, focusses on the short-term and overlooks women's experiences (Wendland, 2007). In addition, the mechanistic application of clinical guidelines has been criticised as undermining maternal autonomy and being at odds with woman-centred care (Greenhalgh *et al.*, 2014; Klein *et al.*, 2007).

Nonetheless, adherence to evidence-based clinical guidelines is often advocated as a route to reduced medico-legal risk (Ransom *et al.*, 2003), and professional guidance is largely silent on the appropriate clinical response when women decline recommended care. In the maternity context, concerns about maternal and fetal safety can lead to conflict (Laufer-Ukeles, 2011), and in some contexts, judicial scrutiny (Paltrow & Flavin, 2013). Clinicians may feel their own autonomy is challenged or that the care preferred by the woman is beyond their expertise; ethical turmoil and medico-legal concerns for clinicians are well documented (Brazier, 2006; Kruske *et al.*, 2013). Pregnant women may face difficulties finding clinicians willing to provide the care they prefer (Charles, 2012) and some have disengaged from hospital maternity care (including 'freebirthing', or birthing at home without skilled attendant) believing that their wishes will not be respected (Dahlen *et al.*, 2011; Ireland *et al.*, 2011). News and social media sources, not-for-profit advocacy organisations and scholars are increasingly highlighting cases where pregnant women's rights to refuse care have been undermined, both in Australia and internationally (Carpenter, 2012; Lewis, 2012; Pascucci, 2015; Pieklo, 2014; Powell *et al.*, 2014; Townsend, 2005; Waters, 2011).

Despite the rhetoric of choice inherent in woman-centred care, there is a substantial body of literature attesting to the, at best, illusory nature of choice in maternity care (Edwards, 2004; Jomeen, 2012; Symon, 2006). Studies have found that women have limited involvement in decision-making and perceive that they are required to accept recommended care (Lewin *et al.*, 2005; Thompson & Miller, 2014). Other studies have found that routine care is rarely presented as a choice (Eri *et al.*, 2011; Stapleton *et al.*, 2002), with examinations sometimes performed without seeking the woman's consent (Rees & Monrouxe, 2011; Scamell & Stewart, 2014). Even where consent is sought, in practice women are "obliged to choose what is set up as the most obvious and sensible option," (Bryant *et al.*, 2007, p. 1192) and power disparities between women and clinicians make it difficult to resist expectations of compliance (Cherniak & Fisher, 2008).

Thus it is clear from that literature that compliance with recommended care is the norm. What remains unclear, however, is what happens when women decline recommended care. The literature focusses on the experiences and attitudes of obstetricians to court intervention (Chigbu *et al.*, 2009; Cuttini *et al.*, 2006; Samuels *et al.*, 2007). Although these studies have generally reported low levels of willingness to seek court orders to compel pregnant women to accept recommended care, they have not investigated strategies that might address ethical and medico-legal concerns of doctors. Similarly, only two studies investigated midwives' attitudes and experiences of caring for women who decline recommended care (Danerek *et al.*, 2011; Thompson, 2013). One of those studies (Danerek *et al.*, 2011) found that Swedish midwives prioritised fetal well-being above respect for maternal autonomy and therefore sought to persuade women to accept recommended care. The second study (Thompson, 2013) reported feelings of vulnerability and anxiety amongst midwives caring for women who declined recommended care, and concluded that access to statutory supervision for midwives is important in these situations. Statutory supervision of midwives, although currently under review in the United Kingdom (Parliamentary and Health Service Ombudsman, 2013), is a process whereby midwives are supported in clinical practice, including support for both midwives and women making difficult decisions and advocacy for women whose choices include declining to follow advice (Read & Wallace, 2014).

Women's voices are largely absent from the literature. Several studies have found that women who declined recommended care such as caesarean sections (CS; Chigbu & Iloabachie, 2007; Iris *et al.*, 2009; Ribak *et al.*, 2011) and blood products (Ribak *et al.*, 2011; van Wolfswinkel *et al.*, 2009), had high rates of adverse clinical outcomes. However, the right to refuse recommended care is not diminished by the likelihood of adverse outcomes (McLean, 2009). Three studies directly engaged women who had (Chigbu & Iloabachie, 2007; Ireland *et al.*, 2011), or intended to (Enabudoso *et al.*, 2011), decline recommended care in a hospital setting. Ireland *et al.* (2011) conducted an ethnographic study with remote-dwelling Australian Indigenous women who declined transfer to urban hospitals, remaining in their remote community to birth and found that the women's decisions were based on their own health, their baby's health and the needs of their older children. The other two studies (Chigbu & Iloabachie, 2007; Enabudoso *et al.*, 2011) were conducted in Nigeria and focused exclusively on CS refusal where women were routinely refused care at the tertiary hospital if they did not agree to the recommended CS. Significantly higher perinatal mortality was reported where women were left with little option than to birth in settings without obstetric support (Chigbu & Iloabachie, 2007). Both Ireland *et al.* (2011) and Chigbu and Iloabachie (2007) concluded that accommodating the needs of women who declined recommended care was safer than continuing to refuse to do so.

Processes to guide clinicians accommodating the needs of pregnant women who declined recommended care have rarely been documented in the literature. Although several papers describe the clinical management of women who declined blood products (Braithwaite *et al.*, 2010; Gupta *et al.*, 2012; Mahoney & Valenti, 2004), only three described processes for discussing and providing care to women with a broader range of refusals (Chervenak & McCullough, 1990; Deshpande & Oxford, 2012; Pinkerton & Finnerty, 1996). Each of those processes retained the option of court intervention, two (Chervenak & McCullough, 1990; Pinkerton & Finnerty, 1996) also sanctioned withdrawal of care, and none reported on their effects in clinical practice. Court intervention is at odds with contemporary notions of obstetric 'best practice' and respect for maternal autonomy. Withdrawing care may also undermine the woman's autonomy, may not be feasible where there are no other care providers to accept a referral, and is associated with higher mortality is some settings (Chigbu & Iloabachie, 2007; Scott, 2010).

In August 2010, one large urban tertiary hospital in Australia introduced a policy to guide communication and documentation when women declined recommended maternity care. The policy directs consultant obstetricians to meet such women to discuss and document their preferences in a Maternity Care Plan (MCP) and to ensure women are informed about the risks of declining, and benefits of accepting, recommended care (see Figure 5). The policy recognises the woman's right to refuse any aspect of treatment and describes the hospital's readiness to provide ongoing maternity care, including that which deviates from other local policies or clinical guidelines.

This policy context presented a unique opportunity to examine a process for discussing, documenting and providing maternity services to women who declined recommended care. A retrospective cohort study that analysed the content of MCPs and described demographics and clinical outcomes of women with MCPs is reported elsewhere (Jenkinson *et al.*, 2015). That study found that during the first three and a half years implementation, only 52 MCPs were created, relating to a narrow range of clinical scenarios and mostly authored by a small subset of obstetricians. Although this suggests that the process was under-utilised, MCPs appeared to enable women to decline aspects of recommended care and clinicians to provide maternity care that may have deviated from hospital policies (Jenkinson *et al.*, 2015). This paper documents women's, midwives' and obstetricians' experiences of the MCP process.

Methods, participants and ethics

This qualitative, interpretive study involved in-depth semi-structured interviews with women, midwives and obstetricians. Approvals were obtained from both hospital (HREC/13/MHS/31) and University (2013001320) ethics and governance committees.

Research setting

This study was conducted in an Australian urban tertiary hospital, with co-located public and private maternity services. MCPs were available for publically-funded pregnant women only, of whom approximately 5,000 birthed at the study site annually. A variety of care models were available, including GP-shared care, hospital-based midwife/obstetrician antenatal clinics and midwifery group practices.

Recruitment and data collection

All MCPs created between August 2010 and December 2013 (n=135) were extracted from the hospital database and examined; 83 were excluded as they related only to complex medical care (see Figure 7). Of the 52 women with MCPs related to declining recommended maternity care, permission to be contacted for research purposes was documented in the medical records of 16. Those 16 women were invited by letter to participate in an interview; nine agreed to be interviewed.

Midwives and obstetricians were recruited via an email invitation from managers, as well as through information sessions provided by the research team.

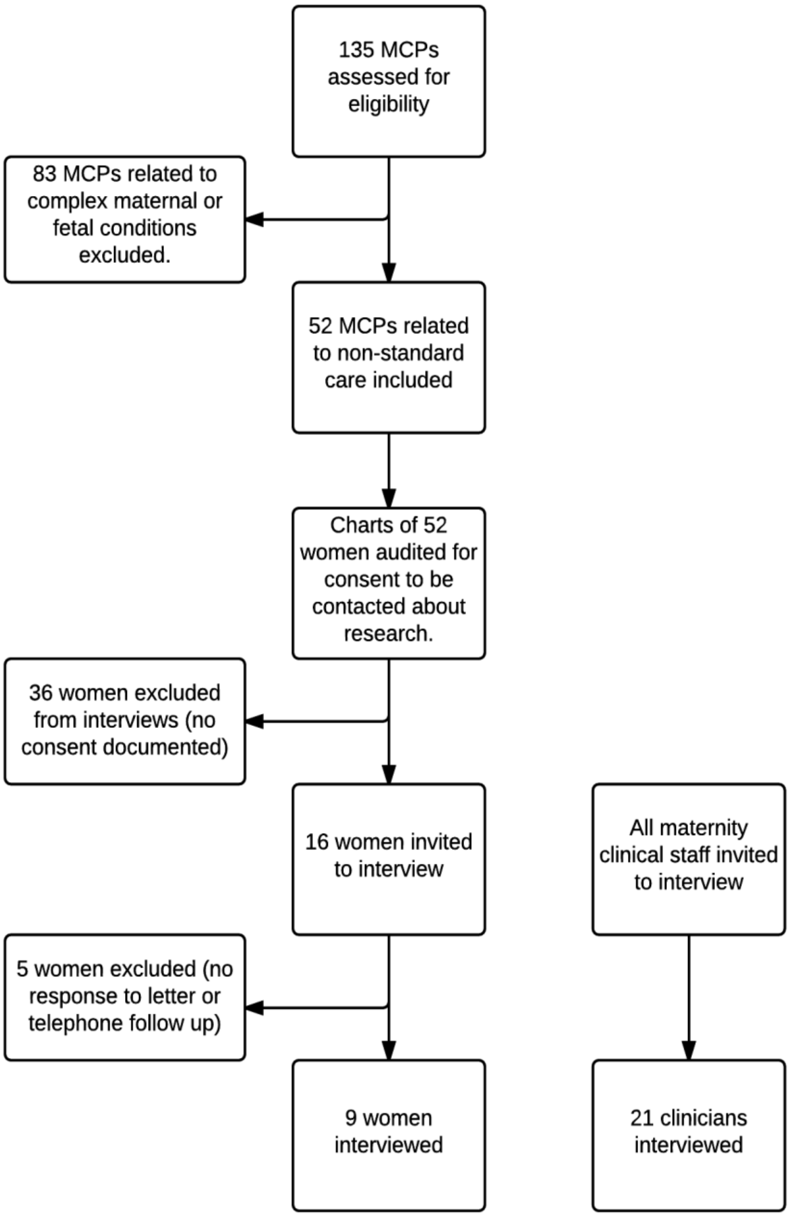


Figure 7: Study inclusion flowchart

In-depth, semi-structured interviews were guided by open-ended questions about the purpose, usefulness and effectiveness of the MCP process since implementation (see Table 3) and also elicited participant demographic data. Most interviews (*n*=22) were individual; three were small group interviews at the request of participants (respectively involving two obstetricians, four registrars, and two midwives). Transcription and preliminary analysis occurred concurrently as interviews progressed, and all individuals who expressed interest in the study were interviewed. Data saturation was observed in each participant group. Interviews were conducted at locations nominated by participants, either at the hospital, in the participant's home or a community venue. Most interviews were conducted face-to-face; two were conducted via telephone at the request of the participant or where the participant no longer resided locally. Prior to the commencement of the interview, participants had the opportunity to read the participant information sheet and ask questions about the study, before consenting to participate. All interviews were facilitated by the first author, in some cases jointly with the second or third author.

Table 3: Interview topics

Clinicians	Women
• Situations which warrant an MCP; • Understandings about the reasons women decline recommended maternity care; • Reactions and concerns when women decline recommended care; • Experiences of, and views on, the MCP policy and process; • Suggestions for improvement.	• Type of care preferred; • Reasons for declining recommended care; • Knowledge and experiences of, and satisfaction with, the MCP process; • Subsequent maternity care in the context of an MCP; • Suggestions for improvement.

Data analysis

Interviews were audio-recorded, transcribed verbatim, and anonymised by the first author before being uploaded to NVivo (Version 10). A thematic analysis permitted insights across the spectrum of experiences amongst the diverse participant group (Braun & Clarke, 2006). Each transcript was read in its entirety by the first author; re-readings followed in order to identify comments related to each participant's views about the purpose of MCPs, the process of creating them, and their impact on subsequent maternity care. Related comments were coded and grouped into themes, which were labelled and defined. The third author read a selection of transcripts and independently created a coding scheme which was compared with the first author's; minor inconsistencies were rectified. Remaining transcripts were coded using this scheme, with adaptations made to accommodate new ideas. Finally, the first author reviewed all data to check for cohesiveness within themes; some themes were sub-divided, and others merged until stable themes were agreed by all authors.

In this paper, quotes exemplifying these themes are attributed to participants identified by group (MW for midwives, OB for consultant obstetricians, R for registrars, W for women) and an individual (e.g. MW3, OB5 etc). Where needed for clarity and brevity, words have been inserted into quotes (denoted by [square brackets]) or omitted (denoted by **…**). Reported speech is indicated by inverted commas. Throughout this paper, the term ‘clinicians’ is used when referring to midwives and obstetricians collectively.

Results

Interviews occurred with 30 participants (12 midwives, five consultant obstetricians, four obstetric registrars and nine women) and had a median duration of 52 minutes. Consultant obstetricians had a median of 7 years post-qualification experience; obstetric registrars were in their first or second year of training. Midwives had a median of 23 years experience and were in clinical roles at the study site.

Women had a median age of 33 years; most were multiparous (n=7/9) and all were partnered and had had singleton pregnancies. Their MCPs most commonly related to declining CS in the context of two (n=4) or three previous CS (n=1), or breech presentation (n=2). Two MCPs were created because women declined continuous monitoring of the fetal heart during a planned vaginal birth after one CS (VBAC1). Most women had vaginal births in accordance with their preferences (n=5); two women consented to CS during labour and another chose not to birth at the study site. Two women had previously been refused care (one by a private obstetrician and one by another public hospital). The women were between two and fourteen months post-partum when interviewed.

Four major themes were identified: i) ‘Reassuring and supporting clinicians’; ii) ‘Keeping the door open’; iii) ‘No guarantees’ and iv) ‘Varied awareness, criteria and use of the MCP process.’ These themes, with exemplar quotes, are explored below.

Reassuring and supporting clinicians

All clinicians and most women who were interviewed acknowledged the professional, medico-legal and personal stress that clinicians commonly experience when women decline recommended care. The MCP process was viewed as ameliorating this stress by establishing a policy context, enabling detailed communication by an obstetrician of perceived obstetric risks to women. The MCP also provided a record of those conversations and alerted other clinicians who might encounter the woman during subsequent maternity care.

All clinicians acknowledged that women had the right to refuse recommended care and expressed a commitment to respecting maternal autonomy.

> *All we can do is document the advice we've given and why we've given it and document what they've decided to do. (OB5)*

> *All you have to do is impart the recommended information… and at the end of the day … it's the woman's choice to make that decision… It's a woman's right to choose. To choose care, and to refuse care and not to be punished for that. (MW11)*

While some of the women were aware that it was their "absolute right" (W11) to refuse recommended care, most seemed quite unable to advocate for themselves and, in some cases, were concerned about their future access to maternity care.

> *Once they said that "we can't make you", and "we're still going to treat you", that made me feel a whole lot better. (W16)*

One woman had felt pressured to consent to a repeat CS but withdrew her consent upon arrival in the operating theatre.

> *I was crying… and as I was walking down to theatre the midwife … said: "Look I probably shouldn't say this, but remember that you don't have to do this." She was … just reminding me that… they can't make a decision for me. (W2)*

It was not until several days after this distressing event that an MCP was created for W2.

> *The doctor… said … I'll just take you off of all of the lists he said. We'll stop bothering you about a caesarean. You obviously don't want to do it… which was wonderful, took all the pressure off. (W2)*

Clinicians' awareness of women's rights to refuse, however, did not prevent them from feeling anxious about the consequences, both medico-legal and personal, of poor clinical outcomes.

> *I think there is still the potential for litigation and the court will decide… Even when you were not responsible... you kind of re-live the trauma… you kind of hold yourself responsible one way or another. (OB4)*

> *If anything happens [poor maternal or fetal outcome] and I'm working outside of [hospital policies]… then I am not covered by vicarious liability. So then, there goes my house! (MW4)*

Clinicians reported that the MCP process was, in part, established to ameliorate the stress associated with providing care outside of hospital policies and guidelines by providing a structured opportunity to inform women about the possible consequences of declining recommended care.

> *[We] sit them down in a cool, calm and collected way and say "ok, here's your choices" and this is what we understand the risks to be and this is why we would advise against that. (OB3)*

Women also accepted the medico-legal purpose of the obstetric consultation.

> *He went over the risks of my choices, which was fine… I do understand that that's what they need to do… to cover their butts legally. (W12)*

However, women and some clinicians reported that MCP consultations involved a kind of "bargaining" (W12) process where continued access to supportive care was presented as conditional upon the woman agreeing to aspects of recommended care (such as continuous electronic fetal monitoring in a VBAC).

> *[I told the doctor] I just need to know whether you are going to support me to do it [VBAC2]… In the end, he was like "as long as you agree to the monitoring." (W13)*
>
> *The consultant would have an appointment with the patient and say that [care preference] is certainly not happening here and you won't find another hospital that will offer you that, you'll have to come halfway with us. (R3)*

Once created, MCPs were circulated by email to obstetricians and midwifery managers (see Figure 5), with an opportunity for colleagues to comment and raise concerns. Obstetricians regarded this step as respectful of their own autonomy and reported that it had contributed to improving the quality of documentation over time. Obstetricians valued both the documentation of their own discussions with women, as well as being forewarned about clinical situations where other obstetricians had counselled women. Although it was reportedly rare for colleagues to raise concerns about a completed MCP, obstetricians felt reassured by sharing their decisions and inviting commentary from their peers.

> *There's some reassurance in … sending it to a lot of people… When no one else has a whinge about what you've written… everyone else must be ok with it. Well, they didn't say anything, so I'm feeling less vulnerable. (OB1)*

Consultant obstetricians acknowledged that more experienced clinicians were better equipped to counsel women about declining recommended care. However, registrars were the frontline medical staff in the Birth Suite (labour ward). As a result, both consultants and registrars valued the support that MCPs provided less experienced doctors, enabling them to interact more positively with women who declined recommended care.

> *The more junior the registrar, the less they are able to explore the reasons around a decision, rather than having a knee-jerk response and saying that's the wrong decision… I would reassure them [registrars] that if a Maternity Care Plan is in place, they'd [the woman] had extensive discussions with a consultant... I would like the registrars to see it as a comforting thing. (OB3)*
>
> *[MCPs] relieve a lot of stress. If ... she's had three Caesars before and wants a VBAC, you tend to think "oh what!" [But] you can see straight away [in the MCP] that the consultant has seen her, they've discussed all the risks ... so instead of ... saying "ok, your request is random and silly and making me uncomfortable", you can [be] ... happy that this has been discussed. (R1)*

Similarly, midwives reported providing care to women who declined recommended care was less stressful in the context of an MCP.

> *I guess practitioners, midwives particularly, just relax a little bit more if a senior doctor has spoken to her about the risks… That's probably the… advantage of them [MCPs]. (MW8)*

Clinicians reported being well versed in the right to refuse but felt vulnerable when caring for women who declined to recommended care. Consistent communication and documentation were regarded as integral to the MCP process, and clinicians reported feeling protected and reassured by this aspect. Women were more tentative about their right to refuse recommended care, in some cases because they feared that withholding consent would endanger their ongoing access to maternity care.

Keeping the door open

Participants perceived that hospital was the safest place to labour and birth and therefore reported wanting to 'keep the door open' between women and clinicians. In this context, participants emphasised the need to build rapport between clinicians and women.

Clinicians described how they believed that if women's preferences were not accommodated, they would be more likely to freebirth. Clinicians regarded freebirthing as a dangerous option.

> *[The woman's preference] might be outside of the recommendations, but the worst thing you can do is flick a woman [refuse to provide care] and say "Sorry, we can't do that"... She's likely to freebirth at home and that could be even worse. (MW11)*
>
> *We would definitely not deny care. So I think, whatever we could do here [in hospital], would always be safer than an unusual choice which I would consider risky being done without [hospital/obstetric] care. So it's always better that it's here, because ... if the situation changes… and they change their mind then ... we can ... relatively quickly assist. (OB1)*

For clinicians, keeping the door open thus meant keeping women engaged in hospital care. However, there were subtle differences in the way less experienced clinicians described this goal. While consultant obstetricians were more likely to describe the appropriateness of hospital birth in terms of ready access to medical or surgical intervention if needed, registrars were more likely to construct this as permission-giving and supervision.

> *I think they [MCPs] are very good things… They allow women to fulfil their wishes and desires in a way that we can [monitor]... We may not agree with what they have said, but we acknowledge their autonomy and allow them to participate in their birth here. (R2)*
>
> *My anxiety would be very high if I was dealing with somebody like that, but I would prefer that she did it through that avenue [at the hospital] than did it at home by herself completely unsupervised. (R1)*

Clinicians' capacity to provide maternity care to women who declined to follow advice was partly attributed to the sophisticated infrastructure and expertise associated with being in a tertiary hospital.

> *There is something about being… in a huge maternity institution that gives us… the sense of security to be able to [provide care outside of hospital policies/guidelines]... There is nothing that walks in the door that we can't respond to. (OB1)*

> *Perhaps it's the experience of providing care to women who choose care outside of recommendations. It might be the fact that we do have access to theatres, very quickly and there's consultant 24 hours and anaesthetist 24 hours. (MW11)*

Clinicians were also aware of other hospitals where women were routinely refused maternity care if they did not comply with hospital policies and two women had been refused care in other settings because of their choices (VBA2C, and VBAC without continuous electronic monitoring of the fetal heart). One such woman described how being refused care left her in "limbo":

> *[The doctor] was just explaining… that it's [VBAC2] against [that hospital's] policy... and if I came to [that hospital] in labour, they would take me straight for a Caesar. Without an option. I politely told him that he needed my consent to do that, and he was very quiet and just… said, "Well I'm terminating your care" and see you later. (W13)*

Obstetricians valued the MCP process because it provided opportunities to build rapport, identify care options that were acceptable to the woman and ultimately, 'keep the door open' between themselves and the woman.

> *[In an MCP consultation] I'm trying not to get them offside… I'm trying to demonstrate that I understand where they are coming from… I would point out that I think what they are choosing is not in the best interests of them and their baby… but I would try to communicate that in a way that didn't judge them … We want to walk out the door [after an MCP consultation] still talking to each other. (OB5)*

For women, keeping the door open was expressed as concern about being seen as "amenable and not difficult" (W11). Some described feeling that they needed to win the support of the obstetrician.

> *I felt like I was trying to charm him [obstetrician]… There was a tension for me… because I knew what I wanted and I had to, somehow, massage this man into… that being ok. (W3)*

Obstetricians also reported that MCP consultations allowed them to elicit the woman's reasons for declining recommended maternity care and that doing so was part of building rapport.

> *It’s always about delving into why … What do you understand about what that means? What do you think will be the good things and the bad things about that? Exploring that with her. (OB1)*

Some midwives, however, perceived that the reasons for women’s preferences were rarely explored.

> *I don’t even know if any woman’s actually been asked why they’re making a particular choice… if that happens, it would be very rarely. (MW4)*

Women similarly reported that clinicians did not necessarily explore their reasons for declining recommended care.

> *He [obstetrician] didn't seem as interested in why I was going with those options as much as with getting his point across that it was incredibly risky for me to do so… midwives and doctors spent a lot of time telling me things, but not enough time asking things. (W12)*

Despite the emphasis clinicians placed on keeping women engaged in maternity care, one woman did not birth at the study site, convinced that her preferences would not be accommodated. Another woman was so unhappy with her experience that she indicated she would opt-out of hospital maternity care in future pregnancies.

> *[The obstetrician said] “You need to know that if you come in in labour, this is what’s going to happen.” Which essentially is like a threat … [So I decided] I’m going to go to [birth elsewhere]. (W3)*
>
> *After my experience and the lack of support, the bullying, manipulation, I have decided that on the balance next time, I would feel much safer having an unassisted birth than going to hospital. (W12)*

Thus, although participants differed in their views about how or if it was achieved, keeping the door open was a widely valued aspect of the MCP process. There was, however, evidence that achieving this goal was very challenging.

Varied awareness, criteria and use of the MCP process

Clinicians gave varying accounts of how the MCP process was implemented and its eligibility criteria. There was a lack consensus over which clinical scenarios warranted an MCP, and also gaps in awareness about MCPs amongst registrars, midwives and women.

There appeared to be no consistent or well-articulated criteria for defining when an MCP was necessary. Most antenatal care was provided by midwives and registrars, and getting an MCP relied on women being referred to a consultant obstetrician. However, midwives and registrars were unaware of which scenarios warranted an MCP and which didn't. Although some obstetricians saw the lack of well-articulated criteria as providing valuable flexibility, others believed defined criteria were needed.

> *There's different thresholds by which people will do that [create an MCP]. There's just a general loose thing… if you need to be clear about the pros and cons and communicate with colleagues … then do [an MCP]. (OB1)*
>
> *I think it would be quite good maybe for us to agree where it [MCP] is appropriate... and we haven't done that. (OB5)*

Although VBAC2 and breech vaginal birth were amongst the most frequent reasons for creating MCPs, some clinicians questioned the need for an MCP in both cases.

> *We [obstetricians] had the same discussion … about breech, because everybody wanted [women planning a vaginal breech birth to have] an MCP… I didn't agree with it, and I still don't. And I won't write one for a breech baby. (OB5)*
>
> *If it was a … standard VBAC2… then I probably wouldn't get too fussed about [an MCP]... I think quite a lot of us [consultant obstetricians] would look at a VBAC2 as being a bit unusual, but not a ridiculous choice. (OB3)*

In the absence of reliable mechanisms to initiate the MCP process, women's initial expressions of interest in declining recommended care could be dismissed. Lack of awareness of the MCP process, particularly amongst antenatal clinic midwives, registrars and women, was a barrier to access.

> *The first person that she's met [and expressed her birth preferences to] has gone "well that's not going to happen." So she actually doesn't even get escalated up the chain [to get an MCP]. (MW6)*

Even where women were identified as possible MCP candidates, there appeared to be no reliable mechanism for registrars or midwives to refer women to an obstetrician specifically for an MCP. Given the restriction of MCP authorship to consultant obstetricians, this created further barriers.

> *[Registrars in the antenatal clinic] will try and get someone else [a consultant] involved and that will depend on whether that's a dedicated appointment [for an MCP] or not. Because if it's not a dedicated appointment then there's a good chance that they [consultant] won't have time to do it. (OB5)*

Most clinicians agreed that MCPs were poorly promoted and hence remained relatively invisible, and inaccessible. Few women were aware of the existence and purpose of their MCP. Some midwives felt that this limited the effectiveness of the process because women with positive experiences weren't able to encourage other women to access the process.

> *I think we should let women know that they [MCPs] exist! ... I think that big group of women [who] are running the gauntlet of "let's hope for the best on the day" would benefit greatly from the opportunity to voice their needs and wants prior to [labour]. But they don't know it [MCP process] exists… That's actually a real disservice for everybody ... because we've stopped other women saying "it's ok", and we've then stopped other women bringing that information to us and… making an informed decision, not when they are in labour. (MW6)*

The lack of awareness of MCPs limited uptake of the process. Obstetricians determined when and if an MCP was necessary, based on their level of comfort with the woman's preferences. This left ambiguity for midwives, registrars and women and limited the potential of the MCP process to engage women in discussing care options with their care providers.

No guarantees

The MCP process was intended to provide some surety to women who wanted to decline recommended care and reduce the need for them to repeatedly discuss and renegotiate their plans. However, even when women had received an MCP, questions were raised about how effective it was, or could be, in guaranteeing future support from clinicians.

Obstetrician preference was to create MCPs late in pregnancy because this made it less likely that it would be superseded or discarded as clinical indications, or the woman's intentions, changed. This delay, however, meant that repeated discussion and renegotiations throughout antenatal care remained likely.

> *Oh, it was always, always conversation about the VBAC plan… "this is not what we recommend, we do recommend you have another Caesar." You know the risks. It was basically just... on repeat. (W13)*
>
> *I looked after one [woman with an MCP] …. who actually succeeded [in having a VBAC2], but [it was] difficult for her … she really had to stick to her guns... Every time she turned up… it was "you realise … the dangers involved." (MW1)*

Obstetricians acknowledged that information about 'risk' was often revisited with women throughout the antenatal and intrapartum period, but perceived this to be routine due diligence.

> *I always just reiterate the risks and make sure they haven't changed their mind over time… Just because they've got a care plan doesn't mean that you're not going to highlight the risks again. (R2)*
>
> *And I think our job is really to... nicely and firmly reiterate the position of the institution … Basically, almost go through the MCP again, and they nod their head because they have been through it, probably more than once! (OB4)*

However, women perceived that these conversations were intended to persuade them to accept recommended care.

> *I'm 37 weeks, I've done my research. I've told you this is what I want. You're not going to change my mind in the next three weeks, so let's just stop having this conversation. (W13)*

MCPs also could not guarantee that women would get the care that had been planned as their MCP could still be disregarded on presentation in labour.

> *I was told that it would depend on the obstetrician on duty. Be prepared that they might not be supportive of my choice and that I might have a bit of push back from whoever was on duty, even though I had an MCP. (W5)*
>
> *Even if the plans are in place, it's still heavily dependent on who's on shift that day… Whether you've got the right combination of midwives and doctors or not. If you don't… that plan… is not worth the piece of paper that it's written on. (MW8)*

> *We [obstetricians] sign the Maternity Care Plan ... in the antenatal clinic but we're not necessarily the practitioner that's landing that in the birth suite. It does get circulated ... and there's an opportunity to ask questions ... but it still doesn't necessarily mean that ... the group of people that land that patient when she comes in [in labour], are necessarily in total agreement with what's been decided. (OB5)*

The credibility and utility of the MCP process rested on obstetric support available at the time of labour and birth. For women declining recommended care, ongoing efforts by clinicians to communicate risk information created uncertainty and were perceived as pressure to consent to recommended care.

Discussion

This study aimed to document clinicians and women's experiences of using the MCP process. The MCP policy recognises a competent adult's right to refuse recommended care but also responds to ethical and medico-legal concerns this may provoke for clinicians, women and the hospital. In this study, clinicians reported feeling at risk medico-legally, professionally and, in some cases, personally, but also wanted to keep women engaged in hospital maternity care. Although clinicians perceived that women's preferences carried additional (and sometimes unacceptable) risks, they were also aware of maternal autonomy. All clinicians reportedly held the view that providing care according to those preferences was safer for the woman and baby, than refusing to do so.

Clinicians reported feeling protected by the MCP process, which increased their willingness to provide maternity care that differed from that recommended by local policies and guidelines. Studies have found that fear of litigation contributes to clinicians' unwillingness to accept patients whose birth preferences were perceived as high risk (Clark *et al.*, 2008) and impacts on women's access to maternity care (Charles, 2012). Reluctance to provide care in this context was evident in the medical-legal and professional concerns expressed by clinicians in this study, and in the accounts of women being refused care at other settings. Documentation and communication, key to the MCP process, are effective medico-legal risk management strategies (Clark *et al.*, 2008; Ransom *et al.*, 2003) and served to reassure clinicians and protect women's access to maternity care.

The MCP policy addresses a gap in the existing professional guidance available to obstetricians and midwives in Australia, and perhaps elsewhere. The right to withdraw care is protected, in all but emergency situations (ACM, 2014; FIGO, 2012; RANZCOG, 2006b), but there is little clarity about when withdrawing care might be appropriate. An Australian medical indemnity provider advises that failure to follow advice could justify terminating the doctor- or midwife-woman relationship (Medical Insurance Group of Australia, 2011, 2013), but obstetricians are advised against unreasonably refusing care (RANZCOG, 2006b, p. 6). It remains unclear when withdrawing care might be warranted, or how doing so can be reconciled with respect for maternal autonomy.

Two women had been denied care at other hospitals as a result of refusing recommended maternity care. While there is universal recognition of a competent adult's entitlement to refuse recommended care, any entitlement to *request* a particular kind of care is more equivocal. If these two women's circumstances were construed as requesting vaginal birth (rather than declining CS), obstetricians could, and perhaps these women's previous obstetricians did, invoke their own autonomous right to "refuse to carry out services which … [they] consider are not in the best interest of the patient" (AMA, 2006, p. 4). In that context, it is significant that the MCP process respected clinician autonomy also, by incorporating opportunities for constructive and critical debate amongst clinicians. Although reportedly rarely used, this step was seen as protecting clinician autonomy, while still guaranteeing women access to hospital maternity care. The MCP process is one way of recognising the unequivocal status of maternal refusal and working out ways to provide care within the confines of a woman's consent.

Processes like the MCP policy may also present an opportunity to reassure women that their right to refuse recommended care will be respected in the hospital setting, though clearly, this was not always the case. This reassurance may then encourage them to engage or remain engaged in maternity care. This is an important consideration given that several studies have reported a connection between women's disengagement from maternity care, epitomised in the decision to freebirth, and their perceptions that their birth preferences might not be respected (Dahlen *et al.*, 2011; Ireland *et al.*, 2011; Kornelsen & Grzybowski, 2012). Clinicians in this study were concerned that more 'high risk' women might decide to freebirth if their preferences were not accommodated by the hospital. Similar concerns are shared by some ethicists who conclude that the best solution is to make hospital birth more attractive to women (de Crespigny & Savulescu, 2014).

The MCP policy may have the potential to support making birth within the hospital acceptable to women who might otherwise avoid it. However, despite all clinicians espousing respect for maternal autonomy and emphasising the centrality of choice in maternity care, the theme of 'no guarantees' was prominent in interviews, particularly in the accounts of women and midwives. This is consistent with the wealth of research highlighting the problematic reality of choice in maternity care (Jomeen, 2012; Symon, 2006) and contributed to women's tentative invocation of their right to refuse. Also, despite the reportedly reassuring policy context, espoused respect for maternal autonomy amongst clinicians, and emphasis placed on building rapport with women, this study identified cases of conflict between women and clinicians that led to the women avoiding, or intending in the future to avoid, birth at the hospital. Without awareness of their own MCP or the MCP process more broadly, women were unaware of the assurance of access to care that the MCP process afforded. This, coupled with the 'bargaining' style reported in MCP consultations created a perception that access to care was conditional upon compliance with at least aspects of recommended care. This indicates how the challenging it may be to ensure that women's refusals are treated respectfully by individual clinicians and appears to have limited the extent to which the engagement potential of MCP process was realised.

Lack of awareness about MCPs and their function may also have contributed to women being denied opportunities to discuss their birth intentions, and hence to access an MCP. In one case, this resulted in a woman receiving an MCP for a VBAC2 only *after* she became distressed while being prepared for a repeat CS because she had felt pressured to agree to it. Several barriers may have contributed to such situations, including lack of awareness amongst front-line clinicians, lack of agreed criteria for MCPs and lack of a specific referral mechanism to initiate an MCP.

Lack of agreed criteria for initiating an MCP may also have contributed to both variation between clinicians and to clinician-centred, rather than woman-centred, criteria. The variation between clinicians was evident in obstetricians' accounts of the contested need for an MCP for VBAC2 and breech vaginal births. Given that women routinely saw multiple clinicians during their antenatal and intrapartum care, this left open the probability that the woman would encounter another clinician who differed in their assessment of, and support for, her choices (and hence, in the need for an MCP). Receiving conflicting advice can contribute to distrust in care providers and dissatisfaction with care (Browner & Press, 1996; Hauck *et al.*, 2011) and, in this study, created uncertainty about continued access to care. Obstetricians also described the criteria in terms of their own need to "be clear about the pros and cons and communicate with colleagues" (OB1), rather than in the context of the woman's desire to confirm their access to supportive care. It was also possible that other women wanted to decline routine aspects of maternity care, but did not receive an MCP. Other studies (Kotaska, 2007; Thompson & Miller, 2014) have found that women were more likely to be informed and involved in decision-making on procedures regarded as discretionary (such as epidurals), rather than on procedures regarded as routine (such as amniotomy or vaginal examinations). It was not possible in this study to discern how, or to what extent, other maternal preferences about such routine procedures were accommodated without an MCP.

The MCP process appeared to have limited success in overcoming the need to repeatedly re-discuss risk information, which was perceived by women and midwives as intended to persuade the woman to accept recommended care. This is consistent with the findings of other studies, e.g. regarding VBAC where women face considerable pressure to accept repeat CS (McGrath *et al.*, 2010). Studies of midwives' (Danerek *et al.*, 2011) and obstetricians' (Cuttini *et al.*, 2006) attitudes when women decline CS have also reported that most regard persuasion as an acceptable option. Indeed, some ethicists argue that doctors have a responsibility to dissuade women from birth choices perceived as risky (de Crespigny & Savulescu, 2014). There remains an underlying tension between respecting maternal autonomy and trying to persuade women to consent to recommended care (Scott, 2010), which was not ameliorated by the MCP process.

One reason clinicians may try to persuade women to accept recommended care is the conviction that it is the safest course for the woman and baby. This view narrowly defines safety in biomedical terms and may downplay other dimensions of safety (psychological, cultural, spiritual) likely to influence women's decision making (Ireland *et al.*, 2011; Kornelsen & Grzybowski, 2012). Fetal risks also tend to "trump" other considerations important to the woman's well-being (Lyerly *et al.*, 2009, p. 35). Although obstetricians reported that they explored woman's reasons for declining recommended care, MCP consultations were not necessarily perceived in this way by women or midwives. A greater emphasis on understanding the "circumstances and beliefs that factor into the woman's decisions" would likely assuage some of the ethical turmoil experienced by care providers who fear a woman's choices could endanger her fetus (Minkoff & Paltrow, 2007, p. 316).

The role of doctors in authorising women's birth preferences appeared to be implied throughout the MCP process. Critics would, rightly, point out that this fails to disrupt obstetric hegemony (Benoit *et al.*, 2010). If women were referred to an obstetrician regarding their birth intentions, the obstetrician determined whether or not to create an MCP and was the sole author of the documentation, which replaced women's own birth plans. This escalation to consultant obstetrician may also have created a barrier and discouraged some women from persisting with their birth intentions. However, given the realities of a hierarchical institutional culture (Katz Rothman, 1989), enabling midwives or registrars to create MCPs may well have diminished the value of the process in the eyes of obstetricians and the institution (and thus the utility of the process), in much the same way that women's birth plans were not accorded status (Jenkinson *et al.*, 2015). Nonetheless, the

MCP policy, which guaranteed continued access to maternity care, created an important symbol of respect for maternal autonomy at an organisational level. Although the practice of individual clinicians was still variable, there were no accounts of women being refused care at the study site. Indeed the study site accommodated the care preferences of women who had been refused care elsewhere. By recognising and acknowledging the socio-cultural context in which clinicians work, where adherence to evidence-based guidelines is regarded as protection from blame and litigation (MacKenzie Bryers & van Teijlingen, 2010), the MCP process represents one hospital’s effort to support maternal autonomy within the context of obstetric dominance.

Limitations of this study

As a qualitative study conducted in one site, the findings of this study may not be readily generalizable to other hospitals. Similarly, the views expressed and experiences recounted by the participants may not have been shared by other women, midwives or obstetricians. It was also beyond the scope of this study to include any direct observations of maternity care provided to women who declined recommended care. This study also did not report on the organisational culture in which the MCP policy was developed and utilised, although we acknowledge that this is likely to impact on its effectiveness and appropriateness.

Participating women had declined a narrow range of recommended care (either recommended CS, or recommended fetal heart monitoring in a VBAC). Also, MCPs were not created for women who refused blood products (covered by a separate local policy) or when they declined care recommended during labour. It was also beyond the scope of this study to examine the experiences of clinicians or women outside the context of documented MCPs.

Conclusion

This paper has documented the perspectives of women and clinicians who used the MCP process during the first three and a half years of the policy’s implementation at the study site. Clinicians felt protected and reassured by the MCP process and the communication it provided and valued keeping women engaged in hospital care. This, in turn, protected women’s access to maternity care.

However, this study has also identified several shortcomings in the MCP process. MCPs could not guarantee favourable responses from subsequent clinicians, especially in the context of their late creation, lack of agreed criteria and fragmented care. Ongoing discussion of risk, perceived by women and some midwives to be pressure to consent to recommended care, was still evident.

Varying degrees of awareness of the usefulness of and criteria for using the MCP process also diminished women’s access to the process. The process could, however, be improved by raising awareness of the MCP process amongst women and frontline maternity clinicians; development of agreed woman-centred criteria for initiating the process; earlier creation of MCPs including enabling women to initiate the process, and a greater emphasis on understanding women’s reasons for refusing recommended care.

Chapter Six: Bringing feminism into the fray

Orientation

In Chapter Three, I described the need for a layered approach to thematic analysis, in which the first descriptive stage of analysis was followed by a more explicitly feminist thematic analysis which aimed to foreground issues of power and dominance. This layered approach to analysis is a key component of the agenda-driven approach developed throughout this study.

Given that feminism has long been concerned with women's autonomy, especially in the context of reproductive rights, there was always an obvious alignment between this study's goals and a feminist analysis. However, undertaking only that more critical analysis may well have alienated the very clinicians who were the "engine of change" in the health service (Freedman, 2016, p. 2069). Many of those clinicians had championed the Maternity Care Plan (MCP) process, which while flawed, clearly had some benefits. It was therefore strategic to undertake the descriptive analysis first (presented in Chapter Five) in order to 'get the comfortable to listen' (see Joralemon, 2010). Additional analysis was also necessary to understand the more complex values, attitudes and behaviours that influence the provision of maternity care when women decline recommended care.

Acknowledging that different versions of reality exist, as transformative ontology does, requires researchers to critically examine "what is missing when the views of marginalised peoples are not privileged" (Mertens, 2012, p. 806). Thus, unlike the previous chapter, this chapter privileges women's voices and draws upon matricentric feminist theory to understand the complexity of power and control when women decline recommended maternity care in medically-dominated, hierarchical hospital settings. In doing so, this chapter attends to the third objective of this study: to develop a feminist understanding of the experiences of women, midwives and obstetricians when women decline recommended maternity care in a hospital setting.

The following chapter reproduces, in its entirety, the paper that was developed on the basis of my feminist thematic analysis. This paper was published in *Midwifery* which is a leading peer-reviewed international journal, ranked 14th of 116 journals in the field of nursing and midwifery. Together with the paper included in Chapter Five, this study was the first to directly elicit women's experiences of refusing recommended care, thus attending to a gap identified in the literature review. Although obstetricians and (less so) midwives *attitudes* have been studied, this study is also the first to explore their *experiences*, and most notably, their experiences outside the context of court-authorised intervention.

The experiences of women, midwives and obstetricians when women decline recommended maternity care: A feminist thematic analysis.

Abstract

Background

Pregnant women, like all competent adults, have the right to refuse medical treatment, although concerns about maternal and fetal safety can make doing so problematic. Empirical research about refusal of recommended maternity care has mostly described the attitudes of clinicians, with women's perspectives notably absent.

Design

Feminist thematic analysis of in-depth, semi-structured interviews with women's (*n*=9), midwives' (*n*=12) and obstetricians' (*n*=9) about their experiences of refusal of recommended maternity care.

Findings

Three major interrelated themes were identified. "Valuing the woman's journey", encapsulated care experiences that women valued and clinicians espoused, while "The clinician's line in the sand" reflected the bounded nature of support for maternal autonomy. When women's birth intentions were perceived by clinicians to transgress their line in the sand, a range of strategies was reportedly used to convince the woman to accept recommended care. These strategies formed a pattern of "Escalating intrusion."

Key conclusions and implications for practice

Declining recommended care situated women at the intersection of two powerful normative discourses: medical dominance and the patriarchal institution of motherhood. Significant pressures on women's autonomy resulted from an apparent gap between clinicians' espoused and reported practices. Implications for policy and practice include a need for specific guidance for clinicians providing care in situations of maternal refusal, the potential value of an independent third-party for advice and advocacy, and the development of models that support reflexive practice amongst clinicians.

Introduction

The right to refuse medical treatment, held by all competent adults and unaltered by pregnancy status, is a central tenet of respectful maternity care (White Ribbon Alliance, 2011). It is well established in case law, midwifery (International Confederation of Midwives (ICM), 2014) and obstetric ethical guidance (FIGO Committee for the Study of Ethical Aspects of Human Reproduction and Women's Health, 2012), and health policy (Department of Health, 1993). However, research about refusal of recommended maternity care has focused on the attitudes of obstetricians (Chigbu *et al.*, 2009; Cuttini *et al.*, 2006; Samuels *et al.*, 2007), and to a lesser extent, midwives (Danerek *et al.*, 2011). These studies have often examined the use of court orders to authorise caesarean sections (CS) on non-consenting women, or been conducted in situations where dissenting women were refused care.

Although court intervention to authorise treatment on competent non-consenting pregnant women is almost unheard of in Australia, choice in maternity care remains illusory (Edwards, 2004), and willing and unwilling compliance with recommended care is commonplace (Thompson & Miller, 2014). When women resist the norm, safety concerns can lead to conflict, as clinicians can feel their own autonomy is challenged, or that the woman's preferred care is beyond their expertise (Perry *et al.*, 2002). Ethical turmoil and clinicians' medico-legal concerns are well documented (Biscoe & Kidson-Gerber, 2015; Thompson, 2013). Inflexible maternity care that fails to meet women's needs has also contributed to rising rates of planned homebirth without skilled attendant (Dahlen *et al.*, 2011; Ireland *et al.*, 2011).

Only a few studies have engaged women who had (Chigbu & Iloabachie, 2007; Ireland *et al.*, 2011), or intended to (Enabudoso *et al.*, 2011), decline recommended care in hospital settings. These studies shed light on women's reasons for declining recommended care, but not on their experiences of doing so. This silence around women's experiences perpetuates their marginalisation (Rich, 1995).

Reclaiming women's bodily autonomy is a longstanding focus of feminism (Rich, 1995), although largely centred on access to abortion and contraception (Weitz, 2003). Rich (1995, p13) distinguished between the experience of mothering as "the potential relationship of any woman to her powers of reproduction and to children" and motherhood as "the *institution* which aims at ensuring that that potential, and all women, shall remain under male control." This distinction, between the experience of mothering as woman-centred and potentially empowering, and the "unequivocally oppressive" (O'Reilly *et al.*, 2005, p9) patriarchal institution of motherhood, enabled feminism to reclaim mothering while securing women "a life, purpose and identity outside and beyond motherhood" (O'Reilly, 2007, p.802).

Woman's enculturation into the institution of motherhood begins long before childbirth, with the ideal woman defined by her status as a mother (Malacrida & Boulton, 2012). As the perception that the fetus has separate rights to the woman has grown (Pollitt, 2003), the expectation of self-sacrificial motherhood has extended into pregnancy (Bristow, 2016) and even pre-conception (Clark-Flory, 2016). Although woman-centred care has become a cornerstone of progressive healthcare policy, there has been a shift in obstetric concern towards the fetus such that "there seems to be a point at which the value of foetal [sic] life begins to outweigh, perhaps not so much the life of the mother, but perhaps her right to self determination, her plans and her choices" (Cahill, 2001, p. 340).

Although medical control of childbirth was (and is) promoted as being about the safety of women and babies, it was (and is) a gender-based oppression (Cahill, 2001; Diaz-Tello, 2016a). The medicalisation of childbirth was predicated on the incompetence and unreliability of women, whether to birth babies or to provide care to birthing women, and led to the ascendancy of obstetrics over midwifery (Cahill, 2001; Fahy, 2007; Murphy-Lawless, 1998). Women's autonomy in childbirth has been further eroded by a culture that focusses on the short-term and trivialises women's experiences (Wendland, 2007).

In August 2010, a large tertiary hospital in Brisbane, Australia, implemented the Maternity Care Plan (MCP) policy to guide communication and documentation when women declined recommended care. The policy directs a consultant obstetrician to meet with such women during the antenatal period to discuss and document their intentions in an MCP, which is then circulated to all obstetricians and to midwifery managers. The policy recognises the woman's rights to refuse recommended care and assures them of ongoing access to care at the hospital, Our earlier studies of the MCP process found that it was used narrowly and inconsistently, and generally not created until late pregnancy, meaning most maternity care did not occur in the context of an MCP (Jenkinson *et al.*, 2015). Also, while we found that the MCP process provided a symbol of respect for maternal autonomy, the larger forces of patriarchy and medical hegemony remained largely unchallenged (Jenkinson *et al.*, 2016). Such findings highlighted the opportunity for a feminist analysis of the experiences of women, midwives and obstetricians when women decline recommended maternity care.

Methods

In-depth semi-structured interviews with women, midwives and obstetricians provided data for a feminist thematic analysis of interview transcripts. The study that was led by a steering committee involving the three authors, as well as obstetric and midwifery leaders from the study site. Interviews were facilitated by the first author, on some occasions jointly with the second author or another academic advisor (as part of the first author's doctoral studies). The first author is not a clinician but has worked extensively as a maternity consumer representative and advocate in Australia. The other authors are both midwives, working in both academic and clinical contexts. The study was approved by hospital and university ethical review committees.

Participant selection and recruitment

The database of MCPs was used to identify potential women participants (*n*=52). These women's charts were audited for consent to be contacted about research, and consenting women (*n*=16) were invited to participate, by letter. Midwives and doctors who had provided care in the context of MCPs and obstetricians who had authored MCPs were recruited via email invitation from hospital managers and information sessions provided by researchers.

Data collection

Interviews followed feminist principles (Oakley, 1981) and were guided by open-ended prompts about refusal of recommended care (see Table 4). Transcription and preliminary analysis occurred concurrently with interviewing, and all individuals who expressed interest in the study were interviewed. Data saturation was observed in each participant group. Most interviews were individual and face-to-face. Three interviews occurred in small groups, involving 2 midwives, 2 obstetricians and 4 obstetric registrars respectively. Two interviews occurred via telephone at participant request. Interview times and locations (hospital, participant's home or community location) were nominated by participants.

Table 4: Open-ended prompts for interviews

Clinicians	Women
• What aspects of recommended care do women sometimes refuse? • How common do you think it is? Is that changing? • Why do you think they refuse? • What are your reactions or concerns when women decline recommended care?	• Tell me about your recent maternity care. • What aspects of recommended care did you prefer to avoid? Why was that important to you? • Who did you express your birth intentions to? What happened after that?

Data analysis

Interviews were audio-recorded, transcribed verbatim and anonymised before uploading to NVivo (QSR International, 2012) for thematic analysis guided by Braun and Clarke's six-step approach (Braun & Clarke, 2006). The first and second author jointly read a selection of transcripts to create an initial coding scheme, which the first author used to code remaining transcripts, with adaptations made to accommodate new ideas. Coding proceeded iteratively, grouping related comments into themes. Further reading within themes and whole transcripts included searches for disconfirming data and enabled themes to be clarified, with some sub-divided and others merged until stable themes were tentatively labelled and defined. All three authors independently reviewed data within each theme. Minor adaptations were made by consensus until stable themes were agreed by all.

This study's overall goal was to informing change in maternity services, and it was therefore strategic to adapt Braun and Clarke's (2006) approach describe above by conducting two iterations of the qualitative analysis. The first iteration took a descriptive approach (reported elsewhere, see Jenkinson, 2016) and focused on participants' experiences of the MCP process. That descriptive thematic analysis was not, however, intended to foreground the underlying values, attitudes and behaviours that influence the provision of maternity care in such situations. Rather, a second iteration of thematic analysis was undertaken with a feminist lens and focused on participants' broader comments about refusal of recommended maternity care (the focus of this paper).

Adopting a feminist approach foregrounded issues of power and dominance, and underpinned engagement with the viewpoints of marginalised participants. This iteration of the analysis therefore inverted the hierarchy traditional in medically-dominated maternity settings, privileging the experiences of women over clinicians, and the experiences of women and midwives, over obstetricians. This approach has provided insights that could contribute to both the literature on treatment refusal in maternity care, and to the feminist goal of recovering and valuing women's experiences (Rich, 1995). It also attends to an apparent gap in midwifery research, where feminist approaches have rarely been reported (Walsh *et al.*, 2015), and recognises that women's stories "were never mere anecdotes, but testimony through which the neglect and abuse of women by the health care system could be substantiated" and change wrought (Rich, 1995, p. xi).

In this paper, quotes are attributed to participants identified by group (MW for midwives, OB for obstetricians, W for women) and an individual (eg MW3, OB5 etc). Numbers were allocated upon invitation, and therefore do not correlate with the number of participants. Where needed for clarity and brevity, words have been inserted into quotes (denoted by [square brackets]) or omitted (denoted by **…**). Reported speech is indicated by inverted commas. Throughout this paper, the term "clinicians" refers to obstetricians and midwives collectively. Clinicians are not distinguished by gender or position since doing so may have made individual participants identifiable. Also, clinician gender was not the focus of this analysis since the oppression of women in maternity care is gendered, not by the gender of the oppressor, but by the gender of the oppressed (Diaz-Tello, 2016a). The medicalisation of pregnancy and birth can be seen as a "system of care designed for the comfort of the men who control the services, rather than for the women they serve" (Murphy-Black, 1995, p. 275). Murphy-Black's notion of "comfortable men" doesn't refer to just males or obstetricians, but to those (regardless of gender or profession) that have been enculturated into contemporary medicalised maternity care.

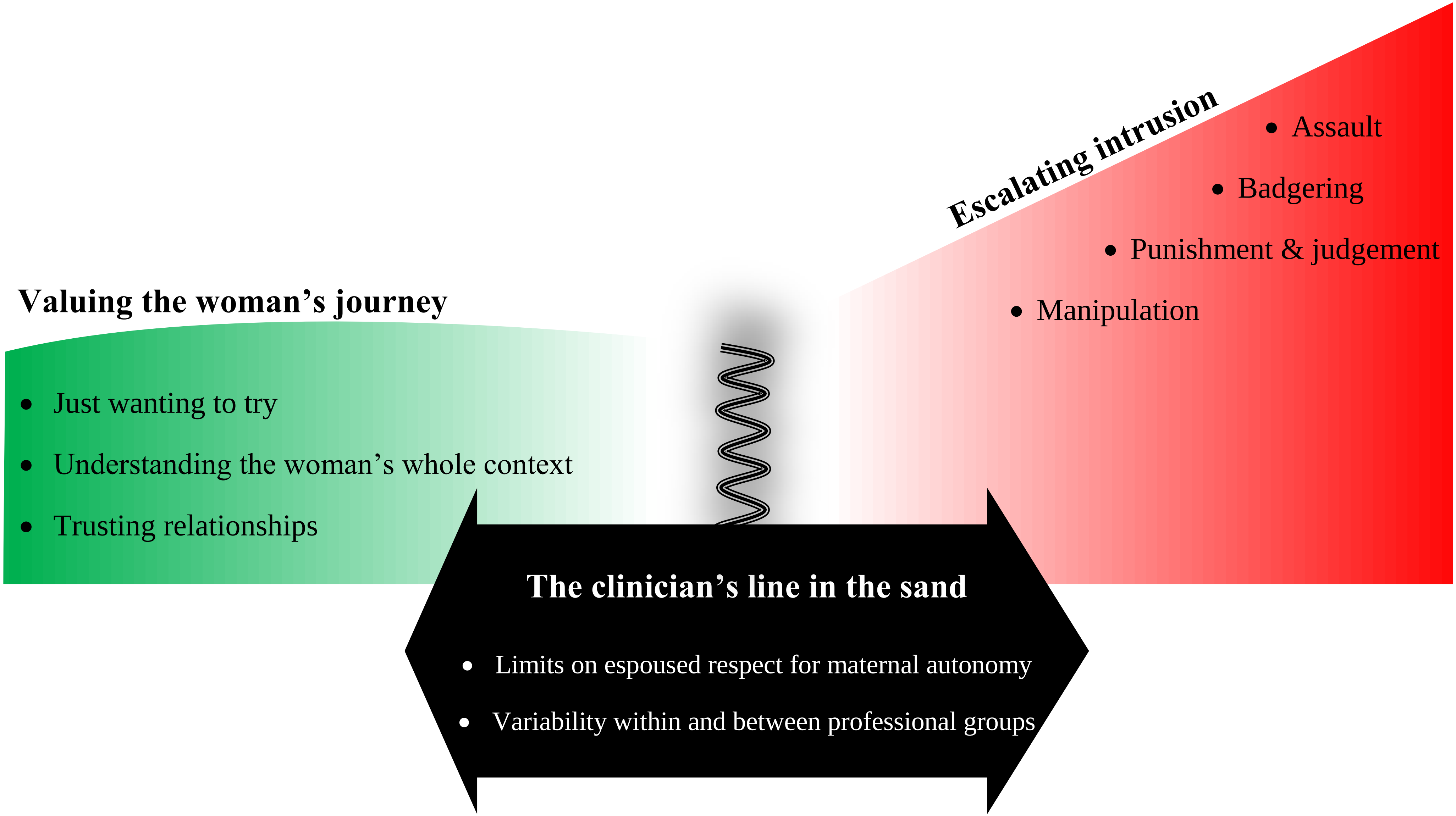
Results

Participants

Thirty individuals were interviewed: nine women, 12 midwives and nine obstetricians. Women had a median age of 33 years. All of the women were partnered, living in an urban area, of Caucasian ethnicity and English speaking. Most (n=7/9) were tertiary educated and multiparous (n=7/9). All had singleton pregnancies, and all infants were live born. During their maternity care, seven of the women had declined CS, in the context of at least two previous CS (n=5) or breech presentation (n=2). Two women had declined continuous monitoring of the fetal heart during a planned vaginal birth after one CS (VBAC1). One woman also declined induction of labour (IOL) after 42 weeks gestation. Most had vaginal births in accordance with their documented plan (n = 6); two consented to CS during labour. One woman chose not to birth at the study site, while two others had previously been refused care in other settings due to their birth intentions. The women were between two and fourteen months post-partum when interviewed. Obstetricians and midwives were all employed in clinical roles at the study site. Obstetricians ranged from being in their first year of specialist training to more than 20 years consulting experience. Midwives ranged from at least 10 years to more than 40 years midwifery experience and were all employed in clinical roles at the study site. Interviews had a median duration of 52 minutes, during which participants recounted their experiences both at the study site and in other settings.

Themes

Three major interrelated themes were identified (Figure 8). Theme one, “Valuing the woman’s journey”, encapsulated care experiences that women valued and clinicians espoused. The second theme, “The clinician’s line in the sand” reflected the bounded nature of support for maternal autonomy. When women’s birth intentions were perceived by clinicians to be across this line in the sand, a range of responses, escalating in intrusiveness, were reported. This pattern of “Escalating intrusion” is captured in the third theme.



Valuing the woman's journey

- Just wanting to try
- Understanding the woman's whole context
- Trusting relationships

Escalating intrusion

- Assault
- Badgering
- Punishment & judgement
- Manipulation

The clinician's line in the sand

- Limits on espoused respect for maternal autonomy
- Variability within and between professional groups

Figure 8: Three inter-related themes

Valuing the woman's journey

This theme including the subthemes: "just wanting to try", "understanding the woman's whole context" and "relationships are key."

Just wanting to try

Women often described refusing recommended care as "just wanting to try." This included having a "very graded" (W11) plan to respond to specific indications in their own labour and birth, rather than accepting interventions in advance.

> *If there was going to be ... something go wrong, I was gonna go have a caesarean... I wasn't going to be stupid, I just wanted ... to try. (W16)*

Clinicians' reported being sensitive to women's desires to attempt her preferred birth and universally acknowledged that it was "extremely, extremely rare" (MW1) for a woman to expose the fetus to excessive risk.

> *[Women] just want… to be heard and know they were listened to, and just try. (OB2)*

No women rejected medical intervention entirely. Rather, they sought flexibility and valued talking about alternatives in order to identify options they found acceptable.

> *It was really talking through with me ... all of these different risks and looking at different decision points… Going through step by step what might happen and agreeing whether I would be ok or not with that. (W5)*

The women valued balanced discussions of risk information, contextualised in their own situations.

> *I felt the information I was being given was both sides… I can't handle that thing where they talk about ... the risks of a vaginal birth, but what are the risks of a Caesar? (W11)*

Understanding the woman's whole context

Women's motivations for declining recommended care were diverse. They attributed their birth intentions to viewing vaginal birth as a rite of passage; wanting to avoid specific experiences encountered in a previous birth; reduced recovery time from vaginal birth over CS, especially in the context of caring responsibilities for older children; desire to maximise the likelihood of a normal birth; belief that vaginal birth would enable easier and swifter bonding with new baby; wanting baby to be born when it was ready (rather than labour being induced), and wanting future pregnancies not to be complicated by multiple previous CS.

Some midwives described how understanding the woman’s broader social world helped them to understand and respect her refusal.

> *She's a mother of four and there's no man on the scene and there is no one that she can say, “look after the kids I've got to go to the hospital and stay there for days”… She didn't want a caesarean because she needed to drive her kids to school, … do the shopping and the cooking. (MW12)*

Although understanding the rationale behind refusals was regarded as ideal, clinicians reported that it was rare for this information to be noted, creating a simplistic picture of women’s needs.

> *The notes say patient declined blood test in pregnancy, so I said “… Are you scared about the needles [or] are you worried about the pain, just physically [or] what it looks like?” [The woman replied] “I don’t want to look at it and I’m worried about the pain…” So … how about if we put Emla cream on the arm and you look away … will you have it then? And she said yes … But the notes say, patient declined. End of story. (OB2)*

It was uncommon for doctors to reveal insight into the complex circumstances influencing women’s decision-making. Instead, they tended to encapsulate the woman’s motivation as pursuing a particular birth experience.

> *I don't really... understand why there is so much emphasis on the actual experience. To me, it seems to be at the expense sometimes of safety. (OB5)*

Conversely, both women and midwives were likely to value the birth experience as an outcome in its own right.

> *There are always situations where a woman will do something that I wouldn't do, but it’s not my journey. It’s only one woman that is going to give birth in that birth room. (MW11)*

> *[Wanting a VBAC3] just stems from that second pregnancy of feeling bullied and ripped off… I guess having caesareans, I hadn't gone through that birthing process… I'd missed out on a really good experience. (W16)*

Relationships are key

Clinicians emphasised the importance of building trusting relationships with women but acknowledged that this was challenging in a busy public hospital.

> *It all comes back to relationship… if she feels like she is respected and listened to… I don't think [we] put enough emphasis on ... relationship building. (MW11)*

Midwifery continuity of carer was regarded as a way of developing these trusting relationships.

> *[The women had] a relationship with that midwife and so they had worked out a lot of ... what they wanted in a way that actually was sometimes not quite so ... risky. [But if] there is no continuity, and there's very little trust ... and there's no relationships. And it's very difficult. (OB5).*

The clinician's line in the sand

All clinicians espoused respect for women's autonomy but invoked a "line in the sand" that bounded their practice and the perceived reasonableness of women's choices. Although both doctors and midwives alluded to boundaries, midwives were most likely to acknowledge them explicitly. The circumstances perceived as crossing the "line in the sand" appeared to depend on the clinician's profession and temperament, as well as characteristics of the woman and her birth intentions.

Although all clinicians espoused respect for women's autonomy, many reported experiencing internal conflict when they feared a woman's choices might adversely affect the fetus.

> *A woman has the right to make any call regarding her health, or the health of her pregnancy or the baby. (OB1)*
>
> *It's a double-edged sword isn't it in some ways? That's that woman's baby and her body and she can do whatever she likes... But ultimately, that baby is kicking around and moving ... it's the potential life ... I really struggle with that. (MW2)*

In practice, this meant that most clinicians described boundaries set by the perceived reasonableness of the woman’s birth intentions. Midwives often expressed these boundaries explicitly.

> *As long as they're not being completely outrageous. You can't advocate for things that ... are so far off the spectrum, it’s ridiculous. (MW8)*

Conversely, doctors often denied the existence of a “line in the sand”, with some suggesting that they were unfairly cast as the villain, and that concerns about their respect for maternal autonomy were baseless.

> *You get the impression from women that doctors are bad… You get that sort of passive aggression sometimes from them [women]… They have that idea that the doctor’s just going to say no. (OB2)*

However, there was slippage in doctors’ talk on this topic. The quote above indicates obstetricians’ acceptance of their own role as authorising women’s birth intentions, while another doctor suggested that support was available for things that were perceived to be only “a little bit different” (OB5) and “not really unsafe” (OB5). In other circumstances, the possibility remained that the doctor’s roles might be to “lay down the law” (OB5).

> *We're not here to ... lay down the law ... We are here to say... if you want to ... do something that is a little bit different, but it’s not really unsafe, then go for it. (OB5)*

The perceived reasonableness of a woman’s choices appeared to depend on her stage of pregnancy, the duration and circumstances under which she persisted with her refusal and perceived risk to the fetus. The first quote referenced in this subtheme (above) revealed how a fetus near term was accorded greater standing in the mind of the midwife. Similarly, declining IOL after 42 weeks gestation was regarded as particularly confronting.

> *[A woman] didn't want to be induced… she was about 3 and a half weeks over [and] … she had some very threatening statements made to her, like “well it’s ok if you want your baby to go to heaven.” (MW9)*

In some cases, the woman’s characteristics also appeared to influence clinicians’ responses to her refusal.

> *I had another lady who was a VBAC who was a qualified midwife and she didn't want monitoring, didn't want a cannula and I was kind of ok with that, so ... it perhaps depends on the personality as well. (MW2)*

Variability within and between clinicians

Both within an individual clinician and between clinicians, the circumstances perceived as crossing the "line in the sand" appeared to vary. Women and midwives perceived that the different professional groups exhibited differing levels of support for maternal autonomy, although the skills and temperament necessary to discuss these topics with women were not universal in either profession.

> *We [midwives] know which doctors are or are not [supportive of women who refuse recommended care]... So we can make sure that she sees a different doctor (MW10).*
>
> *It really becomes a dividing line between the midwives who do and the midwives who don't. There are those who just kind of ... "I come to work, I want to do my job, I want to work by the policies, I'm not comfortable working outside that" ... whereas for others, it's ... all part of the job. (MW1)*

Women often became aware of this variation and accounts of conflicting advice were common.

> *Nearly everyone had a different statistic… [The risk of uterine rupture was described as] under 1% to start with, and then it ended up being like 15-20%, or something… I just kind of drifted off, I wasn't listening. (W16)*

Clinician's previous experience was also widely regarded as determining their response to refusal of recommended care. While having had more experience was regarded as enabling clinicians to have more nuanced discussions with women, recent negative experiences could also lead clinicians to take a more risk-averse stance.

> *I think at the consultant level, we're a lot more cool with it because I think we know that... we can handle it. Whereas I think the registrars tend to be very, a bit more black and white. (OB3)*
>
> *The younger midwives are often very nervous. Some of the older midwives have seen horrendous situations, that then influences both of their behaviour in the same way (MW6).*

There were also accounts of midwives ensuring women saw clinicians known to be more amenable.

> *The midwife ... said "You don't really want to see the doctor that's on at the moment, but the one that comes on at 2 o'clock, you probably want to see" [to discuss declining a repeat CS]... She hid me in a room… We waited in there for three hours. [Then the doctor]... came straight in to see us, had a look at the chart and obviously, she had already talked to him and he was just lovely. (W2)*

Escalating intrusion

When women's birth intentions were deemed to cross the "clinician's line in the sand", a range of increasingly intrusive clinician responses were reported. This escalation is captured in the following subthemes: "manipulation", "punishment and judgement", "badgering" and "assault."

Manipulation

Some women felt manipulated into consenting to recommended care. This could occur when intervention was presented as urgently necessary, which women perceived excluded them from decision-making.

> *They [were] making all of these decisions for me... I should have asked to hop up and walk around for a while, take 5 minutes… re-check the baby… But instead, I just agreed to be rushed off for an emergency caesarean which ... probably wasn't necessary. (W2)*

In other cases, women reported that risk information was misrepresented in order to convince them to comply, with the risks of interventions such as IOL and CS downplayed and relative (rather than absolute) risks cited.

> *I was told continuously [that] if my baby went past forty-two weeks, I was going to double the risk of my baby dying [and] that there is no risk with an induction [for a VBAC]. Her exact words were: "The only risk with an induction is maternal discomfort." (W12)*
>
> *The picture I was drawn by the doctor [about the risks of VBAC2] was that it probably would be ok, but he couldn't go by anything because there weren't enough studies done on my situation to ensure that it would be fine… they said, to be completely safe would be to have a caesarean. (W1)*

Women could also be manipulated when midwives co-opted them to help the midwife by accepting recommended care.

> *I said to her [a woman] "For me to be your advocate, I need a lot of information… I know you don't want to have a vaginal examination, but ... I need all the information I can get. So can I do a vaginal examination and can we do a CTG for a little time? (MW5)*

Punishment and judgement

There were also accounts of punishment and judgement directed towards women who declined recommended care. In both clinicians own descriptions of women, and in the reported speech of colleagues, very negative labels were prominent: "aggressive" (MW6); "stupid" (MW11); "crazy" (W1); "completely bonkers" (MW9); "asking for trouble… naughty" (MW8); "selfish" (MW11); "ridiculous… she's nuts" (MW2); "control freak" (OB4); "manipulative" (OB9). The most frequent judgement was to question whether women who declined recommended care were acting as good mothers.

> *I just can't quite get it ... I still can't think why I would put my experience before the brain of my child. (OB5)*
>
> *My partner was walking past the desk and the staff ... [were] gossiping about [us] "Oh these bloody women… it's all about their experience ... not the safety of their baby" …We laughed about it afterwards… because… as if you've got more vested in my baby than I do! (W11)*

Women's perceptions of this punishment and judgement ranged from feeling as if they were an inconvenience to being aware of more explicit condemnation.

> *I ... get the impression they just want things to go smoothly, so it's easier for them… They* ***probably*** *do care, about patients. (W16, woman's emphasis)*
>
> *It really did feel... like I was being punished for not following her advice… for daring to plan a VBAC at 43 weeks with a "ginormous" baby. (W12)*
>
> *He [doctor] told me that I was crazy going for a normal one after [2CS]! (W1)*

Midwives also gave accounts of both midwives and doctors abandoning women as a kind of punishment.

> *She was almost 42 weeks and one day [and had declined IOL], and I went to … discuss it with a consultant … and the response [from the consultant was] "No… I don't recommend any surveillance of this baby. She'll come back with a dead baby." (MW11)*

> *Say… [a woman's] had two previous Caesars and wants intermittent dopplering… and [the midwife is] sitting down there at the desk because… [the woman] doesn't really want any monitoring. Well, that doesn't mean she wants to be left alone! That's not what she was asking for! … There's a lot of washing your hands of her [the woman]. (MW8)*

For women, being refused care was the ultimate form of abandonment. Two women reported being refused care due to their birth intentions.

> *[It was] devastating… I couldn't understand why he [private obstetrician] agreed to it [intermittent monitoring for VBAC] verbally and then later sent me a letter [withdrawing care]… I felt like a child because I … hadn't been given right of reply, there was no negotiation, all the decision was made by him. [W11]*

Some midwives also reported feeling punished and judged by both medical and midwifery colleagues when providing care to dissenting women. They spoke of feeling "out on a limb" (MW1) and of "being blamed" (MW4) for women's refusals. Battle metaphors like "running the gauntlet" (MW1) were also common.

> *But [the midwife] still got an ungodly bullocking [after a woman declined active management of the third stage of labour]… She got roasted and toasted… It was just the fact that [the midwife had] deviated from what is standard practice and standard practice is synto at the time of birth. (MW8)*

> *You are on your own… Not only have I got to fight the doctors, but I've got to fight the [other] midwives as well. (MW5)*

Badgering

Repeated and prolonged discussions of risk during both antenatal care and labour could also amount to "badgering" (W13) as women could be "railroaded" (MW2) into recommended care, either within a single consultation or over time.

> *The obstetrician ... was just not going to ... let me ... leave the appointment until she had ... it [repeat CS] booked… She was like a little terrier. She wasn't going to let it go. (W2)*

> *The obstetrician came in and started badgering me, telling me "your labour is just going to be like your first, you're not going to be able to do this, you should just go for a Caesar now, why put yourself through all of this trouble" (W13).*

Telling women that their baby could die was often the end-point of this badgering.

> *I said to my midwife that I was still not comfortable with an induction… [she] got the head of obstetrics to come in ... his exact words were: "You seem to want a vaginal birth more than you want a live baby" ... To be honest… I was surprised I got to forty-two plus four before they pulled that. (W12)*

Midwives agreed that the net effect of repeated counselling could be coercive, while most doctors seemed to equate coercion only with assault or withdrawing care.

> *I don't think it [repeated rounds of counselling about risk] ever becomes coercive, because if we don't say no… we don't coerce them. (OB2)*

Assault

The final escalation in response to maternal refusal was threatened or actual treatment without the woman's consent: Assault. Two women reported being told that recommended care would be performed, with or without their consent.

> *[The doctor] got really defensive and angry and raised his voice and said ... "you need to know that if you come in in labour, this is what's going to happen" [intervention which the woman had declined]. Which essentially is like a threat. That's assault. (W3)*

Clinicians also recounted their own experiences of treatment being performed without consent.

> *[I asked a woman who was refusing CS and IOL to] just come in and let us do a blood test, check your blood pressure, do a CTG… [then] that CTG shows the baby is dying and they rush her off to theatre [despite her continuing refusal]… The obstetrician ... said, "I'm willing to stand up in court for this one." (MW12)*

> *I practically assaulted someone last week... She was screaming with her legs together [saying] "No, no one's touching me" ... In reality, she never ever really gave consent, but... we just had to examine her. (OB8)*

Discussion

Woman-centred care is a widely touted gold standard in maternity care, requiring care to focus on the individual woman, incorporating not just her physical needs, but also her social, emotional, psychological, spiritual and cultural well-being (Leap, 2009). However, this feminist analysis of the experiences of women, midwives and obstetricians when women declined recommended care identified significant pressures on women's autonomy. Although most women described some maternity care interactions which they perceived as supportive, all reported some degree of intrusion. Only one woman's account of her birth experience comprised almost exclusively of experiences reflective of 'valuing the woman's journey.' Close examination of that case confirmed that her particular clinical circumstances and a continuing relationship with her care providers, likely provided reassurance and prevented recourse to intrusive measures. That is, this case confirmed the veracity of the themes presented above.

These pressures on women's autonomy arise because declining recommended care situates the women at the intersection of two powerful normative discourses: medical dominance and the patriarchal institution of motherhood. When women's birth intentions were perceived by clinicians to transgress the ideals of motherhood, a range of strategies reasserting clinician authority were reportedly deployed. There was variation between individual clinicians and between professional groups about just when a woman's birth intentions crossed this line, but influences related to the woman's characteristics, proximity to term, perceived risks to the fetus were shared. These negative judgements of women were often made explicit.

Mothers and fetuses

The women in this study resisted patriarchal norms of motherhood as, amongst other things, self-sacrificing and reliant on expert advice (Rich, 1995), however, they remained sensitive to the social value and esteem accorded to mothers and did not want to be seen to be doing "anything stupid" (W16). This perhaps reflects the women's awareness of the judgements made about them. Beyond that, it is only by dismissing their own experiences and being seen to prioritise fetal well-being, that women secure permission to give voice to their own experiences of, and desires for, birth (Schiller, 2015). O'Reilly (2006) argues that feminists have become cautious, too often calling for women's emancipation to benefit children. Reliance on child-centric arguments risks trivialising women's experiences and suggests that women's lives have only contingent value (Pollitt, 2003). Just as women who choose to birth at home may do so partly in a quest for a different kind of maternal identity (Gosden & Noble, 2000), the women in this study constructed their birth experience as important to their own maternal identity. Reclaiming birth experiences changes women's relationship to fear and powerlessness in pregnancy, childbirth and mothering (Rich, 1995).

Clinicians in this study invoked negative judgements of women as mothers and reported concern over fetal well-being. Other studies have similarly described clinicians' beliefs that they, not women, are the fetus' best advocate (Kruske *et al.*, 2013). Although clinicians unanimously acknowledged the rarity of a woman endangering her fetus, such protestations raise the spectre of the unusual woman that would, reinforcing norms of self-sacrificial motherhood. These negative judgements reflect what feminist scholars have described as a "deep discomfort with the notion of women as self-directed social beings, for whom parenthood is only one aspect of life, as it has always been for men" (Pollitt, 2003, p.298).

The proliferation of fetal rights and the concomitant loss of maternal autonomy has been linked with the technologies of medicalisation. For example, auscultation of the fetal heart and ultrasound allow the fetus to be monitored and visualised, while the woman fades into the background (Featherstone, 2008). Likewise, the acceptance of CS into obstetric practice enabled fetal rescue despite its initially appalling maternal mortality (Murphy-Lawless, 1998; Wendland, 2007). It may be no coincidence that women's refusals in this study related to two of these features of contemporary maternity care: fetal monitoring and CS. The specific nature of these refusals challenged both the medicalisation of pregnancy and the personification of the fetus.

Risk and evidence-based medicine

It is also (at least) questionable whether the women's birth intentions really did expose their fetuses to excessive biomedical risk. The women preferred vaginal breech birth or VBAC2 over elective or repeat caesareans, or declined continuous monitoring of the fetal heart. In each case, the evidence is either contested or scant (see Kotaska, 2011b; Rimkoute & South, 2013; Tahseen & Griffiths, 2010). These are situations which involve very small absolute risks of very poor fetal outcomes, although those risks may be more provocative when expressed in relative terms (Minkoff & Marshall, 2016). While this constellation of circumstances is challenging (Lyerly *et al.*, 2007), it is also clear that the "clinician's line in the sand" does not only relate to perceived biomedical risks.

The women in this study universally refused (rather than requested) intervention. This opting-out of the obstetric model may be perceived as challenging physician authority (Cherniak & Fisher, 2008). Refusing intervention is reportedly less likely to attract supportive responses from care providers than requesting intervention (Lothian, 2006). Consistent with that, the women in this study encountered a tendency to favour intervention for fetal benefit, which extended to accounts of clinicians (over) emphasising risks to the fetus, while downplaying risks to the woman. There are (at least) two problems with this approach.

Firstly, it overlooks other considerations that the woman may prioritise, including biomedical risks to herself now and in the future, as well as psychological, social, cultural and spiritual risks (Barclay *et al.*, 2016). Women in this study recognised the biomedical risks attending their choices, but like the Australian Aboriginal women in Ireland's study (2011), their decisions were also calibrated against the needs of their families, their born children, and themselves. Rather than accepting the (often overstated) predictive power of risk statistics (Murphy-Lawless, 1998), the women in this study favoured "just wanting to try", and planned to accept intervention if indicated during labour and birth.

Secondly, balancing maternal and fetal risks (even without over-emphasising fetal risks) invokes a so-called maternal-fetal conflict, pitting the woman against her fetus. This situation is more appropriately conceptualised as a conflict between the woman's autonomy and her care provider's judgement about fetal interests (Harris, 2000; McLean, 2009). Rather than constructing the pregnant woman as a threat to her fetus, who is then in need of rescue by paternalistic clinicians, a "wider gaze" is needed (Harris, 2000, p789). By understanding the social and family relationships, context and constraints on woman's decision making, the pregnant woman and fetus retain their status as a single unit, with fetal well-being best protected by supporting maternal well-being (Harris, 2000; Laufer-Ukeles, 2011). This reflects feminist understandings of autonomy as a relational, rather than individualistic, construct and underpins a broad, comprehensive and bias- and conflict-aware account of refusal (Laufer-Ukeles, 2011). This relational understanding of autonomy is captured in in this study, as understanding the woman's whole context, a significant part of "valuing her journey."

Risk-averse guidelines may justifiably recommend repeat CS, CS for breech and continuous monitoring during VBAC labours, but the mechanistic application of such policies is problematic (Kotaska, 2011a). In this study, two women reported being refused care (at other institutions) and two reported being told that recommended care would be performed without their consent. This exemplifies “a climate of risk reduction at all costs” where “a woman’s autonomy is often lost through our interpretations of the evidence and in our threat of abandonment” (Kotaska, 2007, p177). Evidence-based medicine has become a “powerful means of gender oppression” (Wendland, 2007, p.228), with refusal to accommodate alternatives to recommended care linked with both maternal and fetal deaths (Chigbu & Iloabachie, 2007; Kotaska, 2011b). Numerous scholars have called for more flexible approaches (Chigbu & Iloabachie, 2007; Cuttini *et al.*, 2006; Ireland *et al.*, 2011).

Proponents of evidence-based medicine argue that flexibility is at the heart of the approach, since it requires evidence to be interpreted within the context of the woman’s values, goals and circumstances, relies on strong relationships between clinicians and women, and depends on communicating evidence in ways that women find meaningful (Kotaska, 2011a). That description is closely aligned with what the women in this study sought, but found lacking, in their maternity care: a balanced discussion of biomedical risks contextualised in their own unique circumstances.

Gap between espoused and reported practice

Internationally-accepted medical and midwifery ethical guidance emphasises respect for women’s autonomy (FIGO, 2012; ICM, 2014). However, other studies have identified a misalignment between the positions of professional colleges and the opinions of clinicians’ (Samuels *et al.*, 2007), with clinicians’ more likely to be influenced by personal beliefs and values (Cuttini *et al.*, 2006; Samuels *et al.*, 2007). This study extends such findings, by demonstrating an apparent gap between clinician’s espoused respect for maternal autonomy and their reported practice.

This gap suggests that clinicians may not be aware of the influence of their own values, nor be able to make them explicit to women. This affords women little opportunity to predict how their care provider’s values might influence their maternity care. This unpredictability was experienced by the woman in this study whose private obstetrician had withdrawn care late in her pregnancy, after earlier agreeing to support her planned VBAC. Moreover, both in this and other studies (Cuttini *et al.*, 2006; Jenkinson *et al.*, 2016), there was wide variation in the attitudes of clinicians. Even where women have the opportunity to discuss their birth intentions, fragmented care means that even “carefully negotiated treaties don’t turn out to be reliable” (Perry *et al.*, 2002, p13).

Differences between professional groups

Midwives and women perceived that midwives were more supportive than doctors of maternal autonomy. Feminist and midwifery scholars link the “with woman” origins of midwifery to midwives’ support for birth as a valued rite of passage (Leap, 2000; Rich, 1995). While obstetric thinking has a long history of constructing women’s bodies as flawed and favouring technology and intervention, midwifery’s recognition of the normality of birth is just as longstanding (Murphy-Lawless, 1998). That may account for why many midwives appeared to be more skillful and willing users of the practices encapsulated in “valuing the woman’s journey”, and may have drawn their own “line” further afield than their medical colleagues.

Doctors also appeared less willing to acknowledge the existence of the “line in the sand,” which is consistent with the climate of denial that surrounds the problems of disrespect and abuse in maternity care (Diaz-Tello, 2016a). Such denials are part of the privilege enjoyed by Murphy-Black’s (1995) comfortable men of maternity care. Doctors in this study were likely to equate coercion only with assault and withdrawal of care, overlooking the range of other experiences that, while less intrusive, still exerted great pressure on women to comply. Coercion is “a form of social power over others by which they can be made to act even if they do not wish to do so” (Lamond, 2010, p1). Although doctors tended to deny or minimise the frequency of coercion, they simultaneously described coercive practices. Soaring rates of intervention are often attributed to defensive medicine, but failures in consent processes are also significant contributors to complaints and litigation (Gogos *et al.*, 2011), with some investigations condemning the use of “undue pressure” (Scottish Public Service Ombudsman, 2012, p7).

Midwives and escalating intrusion

Although some midwives may have been more skillful and willing practitioners of “valuing the woman’s journey”, they still reportedly deployed intrusive strategies. Midwives reinforce the status quo of gender, power and medicalization (Pollard, 2011) if they only reluctantly support women’s choices or adopt paternalistic strategies to ensure compliance with recommended care (Jacobson *et al.*, 2013). Participants’ accounts of midwives themselves being punished suggests that recourse to intrusive strategies may also have been prompted by concerns for their own professional safety. Midwives may feel disempowered when practising in some organisational settings, adopting the protective response of practising ‘with institution’, rather than ‘with woman’ (Mander & Melender, 2009; Reed *et al.*, 2016). In order to become part of the power structure, rather than resist it, a midwife may ensure her practice accords with the medicalised culture, even if doing so undermines the woman's autonomy (Mander & Melender, 2009). This phenomenon was evident in accounts of midwives choosing not to provide care to women who declined recommended care or punishing women through abandonment. Even amongst those who continued to provide care, "doing good by stealth" (Walsh *et al.*, 2015, p158) and manipulative strategies, such as co-opting the woman to help the midwife, were recounted. The possibility of practising 'with institution' also stems from employed midwives' contractual obligations to adhere to employer policies (Pollard, 2005), meaning that women's autonomy is closely linked to midwives' ability to practice autonomously (Mander & Melender, 2009).

Implications for policy, practice and further research

Despite the emphasis on respect for maternal autonomy in midwifery (ICM, 2014) and obstetric guidelines (FIGO, 2012), little specific guidance addresses maternal refusal. This study suggests that processes to guide clinicians are needed. Such processes should focus on the elements captured in "valuing the woman's journey." That is, they should afford clinicians and women the opportunity to develop trusting relationships and for clinicians to understand the woman's whole context, including meaningful communication about risk, the woman's goals and all alternative options for care. Such guidance could enable clinicians to locate their "line in the sand" further afield.

This study identified pressures on midwives' autonomy and noted the impact of these on women's autonomy. Others have argued that midwifery autonomy is maximised in freestanding birth centre models of care, but these are rare in Australia (Newnham, 2010). The eligibility criteria frequently adopted in such models of care would also exclude most, if not all, of the women in this study. The appropriateness of allowing such eligibility criteria to undermine women's autonomy is questionable (Scamell, 2014). Private midwifery models of care may overcome some of these barriers, but also remain rare in Australia and operate in a precarious regulatory framework (Wilkes *et al.*, 2015).

An English study of midwives' experiences of maternal refusal supported statutory supervision in these situations (Thompson, 2013). Statutory supervision of midwives, although currently undergoing significant change (Department of Health, 2016), was a process in the United Kingdom whereby midwives are supported in clinical practice, including support for midwives' and women's decision-making and advocacy for women whose choices diverge from advice (Read & Wallace, 2014). There is currently no equivalent to statutory supervision of midwives in Australia, although it is under consideration (Nursing and Midwifery Board of Australia, 2013). Access to an independent third-party for advice and advocacy could enable midwives to maintain “with woman” practice and avoid “escalating intrusion.” It could also provide important quality assurance that women are well informed about risks and alternatives which would help to protect women and clinicians alike.

The gap between espoused and reported practice also suggests more reflexivity is needed amongst both doctors and midwives. While reflexivity is widely embedded in undergraduate courses, it is really only explicit in the continuing practice of mental health professionals. Models need to be developed in Australia to support maternity clinicians to practice more reflexively.

Limitations

As a qualitative study conducted in one site, the findings of this study may not be readily generalisable to other hospitals, though it is important to note that some participants described experiences from other hospitals. Similarly, the views expressed and experiences recounted by the participants may not have been shared by other women, midwives or obstetricians. We also acknowledge the participants in group interviews may have answered with more or less candour than those who participated in individual interviews.

This study was limited by the recruitment of participants from one hospital where the MCP process provided at least symbolic respect for maternal autonomy. This suggests that the organisational “line in the sand” may have been more progressive than in other settings, even though the MCP process was used rarely and only for a narrow range of clinical scenarios (Jenkinson *et al.*, 2015). Further research is needed to understand whether a structured documentation and communication process can support respectful maternity care when women decline a recommended care in a range of maternity care settings. Also, the women in this study were relatively socio-economically advantaged. Further research is needed to understand the experiences of women from a broader range of backgrounds.

Conclusion

This paper reported on a feminist analysis of women’s, midwives’ and obstetricians’ experiences when pregnant women declined recommended care. Despite alignment between the care interactions valued (and in some cases experienced) by women and those espoused by clinicians, a range of negative interactions characterised by increasing intrusion were also reported. The demarcation between positive and negative care experiences was “the clinician’s line in the sand.” This mobile and implicit boundary was influenced by patriarchal conceptions of motherhood, a perception of separate fetal personhood, and medical authority.

Chapter Seven: Legitimising Agenda-driven Research

Orientation

This thesis is situated in a context of over-medicalised "too much, too soon" (Miller *et al.*, 2016, p. 2176) maternity care where women's experiences are punctuated by "a startling range and level of disrespectful and abusive treatment, in countries both rich and poor" (Freedman, 2016, p. 2068). Calls for reform of maternity services, in which women's concern over their autonomy have been prominent, are persistent and longstanding, both in Australia (Hirst, 2005) and internationally (Birthrights, 2013; Bohren *et al.*, 2015; Bowser & Hill, 2010; Chalidze, 2009; Declercq *et al.*, 2013; Department of Health, 1993; White Ribbon Alliance, 2011). This thesis, therefore, set out to support women's rights to decline recommended maternity care by promoting the need for systems-level responses to refusal.

The preceding three chapters (Chapters Four, Five and Six) have presented findings from a mixed methods study that sought to answer the question: *Can a documentation and communication process support pregnant women's rights to refuse recommended maternity care?* The study site's MCP process was reportedly intended to support women who declined recommended care, but this study has found that it did this only indirectly. The MCP process served mainly to reassure clinicians by endowing women's birth intentions with obstetric authorisation. Nonetheless, the MCP process did protect women's access to care and enable clinicians to provide care that was contrary to other local policies. This study also documented a gap between clinician's espoused practices and the experiences reported by women and midwives. These preceding chapters addressed the first three objectives of this study.

The fourth objective of this study was to describe an activism-oriented methodological approach that may be useful to researchers seeking to drive woman-centred systems-level reform in maternity services. This objective was developed because although there is a wealth of literature confirming the challenges of affording women meaningful choice and control in maternity care (Bryant *et al.*, 2007; Cherniak & Fisher, 2008; Edwards, 2004; Jomeen, 2012; Lewin *et al.*, 2005; Mander & Melender, 2009; Symon, 2006), evidence and activism, separately, have often been insufficient to change practice (Daellenbach & Edwards, 2010). Simultaneously, activism-oriented research remains largely unexplored Health Services Research (HSR). The decision to base this study on the transformative paradigm, and more specifically feminism, in order use the research to support women's rights to decline recommended maternity care, therefore required an expansion of existing frameworks.

The following chapter reproduces, in its entirety, the paper that was developed to describe and legitimise the agenda-driven approach developed in this study. It is currently under review with *Qualitative Health Research*, a leading peer-reviewed international journal in public health and health services.

This paper will make a significant contribution to the literature by furthering the methodological conversation in HSR and supporting approaches that are useful for conducting research where the goal is health services reform.

Legitimising Agenda-driven Research to support change in maternity services

Abstract

Calls for reform in maternity services are longstanding: Intervention rates are high, care is medicalised, and disrespect and abuse are increasingly regarded as human rights issues. Despite calls for Health Services Research (HSR) to be used to support policy and system reform, to date commonly employed HSR methodologies do not accommodate strategic, activist orientations explicitly. This article describes a HSR project that aimed to support women's rights to decline recommended maternity care and promote the need for systems-level responses to refusal. The adoption of an activist orientation was underpinned by the transformative paradigm. However, the transformative paradigm has received little attention in HSR and existing transformative frameworks were only partially relevant to the HSR context. We therefore developed a different approach: Agenda-driven Research. The cornerstone of Agenda-driven Research is redefining the intended audience of the research, to include not just those who benefit from it, but also those in empowered change-enabling positions. It is a useful approach for those interested in using research to support patient-centred reform in health services.

Keywords: mixed methods; transformative; health services research; maternity care; feminism; autonomy; refusal of treatment.

Background

The vast literature focused on dissemination and translation attests to the desire of scholars to conduct research that ‘makes a difference’ (even beyond the obvious funding imperatives). Researchers interested in improving systems of healthcare may turn to Health Services Research (HSR) and be “drawn to the complexity of health systems and seeking to support change within them” (Sheikh *et al.*, 2011, p1). Health Services Research aims to produce “reliable and valid research data on which to base appropriate, effective, cost-effective, efficient and acceptable health services” (Bowling, 2014, p. 18). However, too often research outputs are not embedded in clinical practice, and may fail to engage the people at the front-lines of health systems on whom change depends (see Freedman, 2016).

To date, HSR has been dominated by positivist (quantitative) methods most familiar to, and valued by, senior clinicians and funders (O'Cathain *et al.*, 2007). While a “quiet revolution” (O'Cathain, 2009, p. 3) has seen the growing acceptance of qualitative and mixed methods to broaden HSR’s field of view, a need remains to “think more deeply about how to support policy and system change through… research” (Gilson *et al.*, 2011, p4). Explicitly articulating a reform agenda may challenge claims to neutrality and objectivity (Cairney & Oliver, 2017), but it is also an opportunity to be more transparent about the “sociocultural dimensions” that underpin research (Lupton, 1997, p. 28).

Meanwhile, the transformative paradigm informs the work of researchers seeking to “address inequality and injustice in society” (Mertens, 2007, p. 212). Sweetman *et al.* (2010) built on the earlier work of Mertens (2003) to explicate criteria for rigorous transformative mixed methods research (see Table 5). Such research references a problem in a community of concern, that is, a group whose members are in some way oppressed, marginalised, or underrepresented. Members of that community may initiate the study and be actively engaged in it. Transformative researchers use various theoretical lenses including feminist, critical and disability rights theories (Mertens *et al.*, 2010) and examine research questions which embed advocacy stances (Sweetman *et al.*, 2010). The literature reviewed in rigorous transformative research should attend to matters of diversity and oppression and appropriate labelling of the participants (Sweetman *et al.*, 2010). Finally, the research will yield data and outcomes that interrogate power relationships, facilitate social change and benefit the community (Sweetman *et al.*, 2010). It is this point which sets transformative research apart from translational. The aim of transformative research is not just the translation of research findings, but the conduct of research in ways that aim to benefit marginalised people.

Table 5: Criteria for rigorous transformative mixed methods research

(Source: Sweetman, Badiee and Cresswell, 2010, p442-3)

- Reference a problem in a community of concern, whose members may initiate the research, and/or be actively engaged in the project
- Declare a theoretical lens
- Research questions written with an advocacy stance
- Literature review includes discussions of diversity and oppression
- Discuss appropriate labelling of participants
- Data collection and outcomes benefit the community
- Results elucidate power relationships and facilitate social change
- State use of a transformative framework.

While participatory methods have gained some traction in HSR (see Abma *et al.*, 2009; Kendall *et al.*, 2011), such approaches may not necessarily be activist in orientation nor be designed strategically to engage and influence change-makers. In this article, we describe the conduct of our recent study of refusal of recommended maternity care, which was founded on the transformative paradigm and had the explicit goal of promoting the need for systems-level processes to support women's rights. Informed by HSR, we adopted a pragmatic and applied approach to all decisions regarding design, methods, analysis and dissemination, however we also located the study within the transformative paradigm and drew on feminist theory to develop a more critical understanding of the sharply gendered issues of power and control that may arise when women decline recommended maternity care (Jenkinson *et al.*, 2017; Jenkinson *et al.*, 2015, 2016). Although Sweetman *et al.* (2010) developed their criteria (see Table 5) to address a perception that mixed methods researchers were not attending to matters of advocacy, we found that their criteria did not fully accommodate the strategic approach needed to achieve our activist goals in a HSR context. In this article, we have two aims: to raise awareness of the value and importance of transformative Health Services Research and to describe a methodological approach that used research to support women's rights to decline recommended maternity care by promoting the need for systems-level responses to refusal. The following sections summarise the findings of our study, before explaining how we expanded upon Sweetman *et al*'s (2010) criteria to build a methodological bridge between transformative and Health Services Research. We argue that this approach is useful to researchers seeking to drive woman-centred systems-level reform in maternity services, and patient-centred reform in health systems more widely.

A study of treatment refusal in maternity care

In 2014, we undertook a research project that sought to support women's rights in maternity care by promoting the need for systems-level responses to refusal of recommended care. The study was conducted in a large tertiary maternity service in Brisbane, Australia, where a system of universal public healthcare provision operates in parallel with a private healthcare system. At the study site, several models of care are available to the 5,000 women who birth within the public maternity service annually, including midwifery group practice; GP-shared care; midwifery and specialised obstetric or other specialist clinics (e.g. diabetic, maternal-fetal medicine). At the study site approximately 30% of women birth by caesarean section (CS), a rate broadly similar to rates reported across Australia (Australian Institute of Health and Welfare, 2015).

The study site was chosen because, in 2010, it had implemented the Maternity Care Plan (MCP) process to guide communication and documentation when pregnant women declined recommended care. The accompanying policy recognises the woman's right to decline any procedure and assures her of ongoing access to care at the hospital, even if that care is contrary to other local policies and guidelines. The existence of the MCP policy suggested that despite other indicators of medicalisation (such as the CS rate mentioned above), the culture was more progressive than in many other settings in Australia. Indeed there is a substantial body of literature attesting to challenges of affording women meaningful choice and control in their maternity care (Bryant *et al.*, 2007; Cherniak & Fisher, 2008; Edwards, 2004; Jomeen, 2012; Lewin *et al.*, 2005; Symon, 2006). In many settings, including the study site, intervention rates are high and care is medicalised. This "too much, too soon" phenomenon, prevalent in high-resource settings, is increasingly regarded as an issue of respectful maternity care, along with the more overt forms of disrespect and abuse that are now well documented in some low-resource settings (Freedman, 2016, p. 2176; Miller *et al.*, 2016).

The impetus for our study of refusal of recommended maternity care came from Australia's national maternity consumer advocacy organisation (then, Maternity Coalition; MC, now Maternity Choices Australia). With the support of two midwifery academics (Authors 2 and 3), an MC leader, (first author) developed a proposal to undertake doctoral studies exploring this issue. A study reference group, comprised of these three researchers and senior clinicians at the study site, developed and undertook a sequential mixed methods study to explore the research question: *Could a documentation and communication process support pregnant women's rights to decline recommended maternity care?*

The results of that study are reported in detail elsewhere (Jenkinson *et al.*, 2017; Jenkinson *et al.*, 2015, 2016). The initial quantitative phase was a retrospective cohort study (*n*=52) comprising chart audit, review of demographic data and clinical outcomes, and content analysis of MCPs. Findings indicated that while MCPs enabled clinicians to provide care outside of hospital policies, they were utilised for a narrow range of situations, with significant variation in their application (Jenkinson *et al.*, 2015). The subsequent qualitative phase involved semi-structured interviews with women (*n*=9), midwives (*n*=12) and obstetricians (*n*=9) recruited via the retrospective cohort study. Transcripts of those interviews were subjected to two layers of thematic analysis. The first layer of analysis was descriptive and focused on participant's experiences of the MCP process. That analysis (Jenkinson *et al.*, 2016) found that clinicians felt protected and reassured by the structured documentation and communication and valued keeping women engaged in hospital care. This, in turn, protected women's access to maternity care. However, inconsistencies in the implementation of the MCP process, and fragmented care, diminished both the utility of the process and women's access to it. The second stage of thematic analysis applied a more critical and feminist lens, foregrounding the underlying values and attitudes that drove care when pregnant women declined to follow professional advice (Jenkinson *et al.*, 2017). That analysis identified both supportive and punitive interactions between women and clinicians, depending on whether the woman's birth intentions were perceived by individual clinicians to transgress norms of motherhood and patienthood. We theorised that in the context of medical hegemony and patriarchy, systems-level processes, such as a refined MCP approach, could support clinicians to more consistently use supportive approaches, potentially staving off more punitive measures (Jenkinson *et al.*, 2017).

The community of concern and the intended audience

Central to Sweetman *et al*'s (2010) criteria is that transformative research should reference a problem in a community of concern, where members of that community may initiate the study and engage in it. Our study was initiated by a maternity consumer advocacy organisation and women's concerns over their autonomy in childbirth have been well-documented both in reviews of maternity services in Australia (Hirst, 2005) and internationally (Department of Health, 1993), as well as in other scholarly, activist and media sources (Birthrights, 2013; Carpenter, 2012; Lewis, 2012; Pascucci, 2015; Pieklo, 2014; Powell *et al.*, 2014; Scottish Public Service Ombudsman, 2012;

Townsend, 2005; Waters, 2011). Women's autonomy is also central to what is increasingly understood as a human rights issue: respectful maternity care (Bohren *et al.*, 2015; Bowser & Hill, 2010; Chalidze, 2009; White Ribbon Alliance, 2011).

Although maternity consumer advocacy organisations are well organised and readily identifiable in Australia, engagement with them and their members as co-researchers has been rare. These organisations can be seen as part of an emancipatory patient-movement (Williamson, 2008) and collaboration with them is fundamental to transformative research in the maternity setting. Indeed in maternity care where the interpretation of evidence is often directed by the "professional projects" of either midwifery or obstetrics, the inclusion of consumers as co-researchers may "lead to a [more] balanced interpretation of the evidence" (Downe, 2015, p. 1).

However, engagement with the community of concern was necessary but not sufficient for achieving the transformative goals of our study. Maternity care is an interaction between women, doctors and midwives where the experiences of women who decline recommended care depend largely on the practice of clinicians. In maternity care, the medicalisation of women's bodies and obstetric dominance, long critiqued by medical sociologists, feminist and midwifery scholars (see Allsop, 2006; Coburn & Willis, 2000; Davis-Floyd, 2008; Fahy, 2007; Katz Rothman, 1989; Murphy-Lawless, 1998; O'Reilly *et al.*, 2005; Oakley, 1984; Reiger, 2010; Rich, 1995; van Teijlingen *et al.*, 1999), come together to create a "system of care designed for the comfort of the men who control the services, rather than for the women they serve" (Murphy-Black, 1995, p. 275). The term 'comfortable men' refers not only to males or to obstetricians, but recognises that whatever a clinician's gender and profession, those that have been enculturated into contemporary medicalised maternity care are made comfortable by its operations, not the women they serve. In that context, progress towards woman-centred care depends on first engaging those 'comfortable men' and problematizing some of the comforts of their empowered positions. It is to this idea that medical anthropologist, Joralemon referred when he concluded that "it is hard to 'afflict the comfortable,' if they are not listening" (Joralemon, 2010, p. 100).

In facility-based maternity care, clinicians practice in a culture defined by obstetric dominance (Murphy-Lawless, 1998; Reiger, 2008), risk aversion (Ballantyne *et al.*, 2016) and defensive practice (Cheng *et al.*, 2014; Pollard, 2005). In that context, compliance with clinical guidelines is regarded as protection from litigation and professional censure and may supersede ideals of woman-centredness (Kotaska, 2011a). Although in the current study the wording of the MCP policy document strongly affirmed women's rights to refuse recommended care, this was inconsistently reflected in the views and experiences of participants, substantiating the existence of well-established gaps between policy and practice (Diaz-Tello, 2016a; Freedman, 2016).

Therefore, and beyond engaging with the community of concern, we identified the intended audience of our research as clinician leaders and policy makers in health services who were in a position to create and sustain change. This approach sought to engage Freedman's (2016, p. 2069) "engine of change" by conducting research that attends to the concerns of women, in ways that engage decision makers. Study site senior managers, obstetric and midwifery leaders were actively involved in the design and conduct of the study, alongside the consumer researcher. The engagement of these leaders enabled the study to be carried out and afforded it credibility in the eyes of participants who might otherwise have chosen not to participate. It also maximised the likelihood that recommendations arising from the study's findings would be adopted at the study site, and considered by other health services.

Also, by understanding the 'problem' of maternal refusal from the perspective of empowered participants such as obstetricians, we could find ways through the culture, rather than hope to revolutionise it. Indeed, the value of studying 'elites', such as doctors, has often been overlooked in transformative research (Schneider & Aguiar, 2016). Our recommendations attended to clinicians' needs, health service needs *and* women's needs. This approach was strategic, not just practical. Practicality alone could mean that research "may serve whatever ends policy makers endorse [and not be]… premised on higher social goals than being useful to those in power" (House & Howe, 1999, p. 36). Although Sweetman *et al*'s (2010) criteria stop at referencing a problem in a community of concern, we propose that transformative HSR should be designed to engage an expanded intended audience, specifically including those in empowered change-enabling positions.

Research questions and literature

The conduct of our study developed strategically to engage our intended audience, beginning with convening the reference group. Consistent with Sweetman *et al*'s (2010) criteria, our activist orientation was reflected in both the emphasis on systems-level responses (the utility of the MCP process) and the inclusion of women's voices which are largely absent from the literature on this topic. However, the research questions and objectives were also developed with the intention of engaging doctors and policy makers in health services, as this engagement was (and continues to be) integral to progressing our agenda.

Likewise, our literature review was keenly focused on the marginalisation and oppression of pregnant women who decline recommended maternity care, through three foci. In each of the publications arising from the study, we documented a burgeoning literature that demonstrated the difficulties women face when declining recommended maternity care. Secondly, we documented the exclusion of women's voices from the extant literature on this topic, which perpetuates their marginalisation. These first two foci concentrated on the oppression of women who decline recommended maternity care, however, the third focus of our literature review was on documenting the lack of research about guidance for clinicians accommodating the needs of pregnant women who decline recommended care. The decision to include literature about systems-level responses in our review recognised that it was not sufficient to document the nature of the problem, but by understanding the context in which women's refusals occur, we were better able to identify ways to protect and promote their autonomy. The importance of including literature about system-level responses was therefore an important expansion to Sweetman *et al*'s (2010) criteria reflected in our approach.

Language choices

Sweetman *et al.* (2010) further recommend explicitly discussing the labelling of participants, but we focused on using labels that were both empowering to participants and familiar to our intended audiences. For example, although the language of the study site referred to 'women who *requested* non-standard care,' we used the label 'women who *declined* recommended care.' This was a strategic decision made to engage stakeholders at the hospital and foreground the distinction between requesting and refusing care. This distinction is important because while there is universal recognition of a competent adult's entitlement to *refuse* recommended care, any entitlement to *request* a particular kind of care is more equivocal (Minkoff, 2006). Beyond this, we largely omitted explicit discussion of labelling, since doing so would have been unfamiliar and distracting to the audience we sought to engage.

Delivering benefits to the community

According to Sweetman *et al.* (2010), transformative research should benefits the community of concern, notwithstanding the capacity that this implies researchers have to predict how findings will be used in practice (Ginsberg & Mertens, 2009, p582). To maximise the likelihood that our research would benefit women, we started with the (quantitative) methods that doctors and health service policy makers were most likely to value. This is consistent with Hodgkin's (2008, p19) conclusion that researchers "seeking to influence the policy and practice agenda around women's issues might consider the types of data that are most highly regarded by the audience they are seeking to persuade."

We also included a qualitative phase as women's and midwives' voices were essential to the transformative goals of this study. However, the reporting of findings from the qualitative phase of the study was challenging. The unfamiliarity and low regard for qualitative methods amongst many medical staff meant that careful negotiation and awareness-raising were required build shared understandings about rigour in qualitative research. This process was necessary to ensure results were seen to be legitimate and trustworthy. Negotiation and awareness-raising with power-holders should be seen as integral to transformative research, and was another important way that we expanded upon Sweetman *et al*'s (2010) criteria.

A nuanced approach to examining power relationships

Sweetman *et al*.'s (2010) criteria also call for transformative research to illuminate power relationships, but we found that a more nuanced approach was needed. Our agenda to support women's rights in maternity care through systems-level responses to refusal of recommended care drove the decision to conduct a two-layer thematic analysis (described earlier). The descriptive layer of the analysis may be perceived to be superficial but had we omitted it, and offered only the feminist reading of the MCP process, the result may well have appeared to condemn the use of formal documentation and communication processes, or been dismissed as overly critical by our intended audience. The MCP process may have been flawed, but it also appeared to have some benefits, particularly to clinicians who were reassured by it. This, in turn, protected women's access to care, irrespective of their birth intentions. The descriptive layer of our analysis was strategically important to get the "comfortable men" (Murphy-Black, 1995, p. 275) to listen so that we might promote a more woman-centred approach. However, stopping at this descriptive layer would have overlooked the more complex, power-laden story that also needed to be told. These aspects were taken up in the feminist layer of thematic analysis. This more nuanced approach refines Sweetman *et al.*'s (2010) notion of examining power relationships in ways that enabled our study to go beyond documenting the problem, to contributing to possible solutions and supporting woman-centred reform in maternity services.

Our study linked shortcomings in respectful care to patriarchy and obstetric dominance, and recent history demonstrates their intractability in Australia (Reiger, 2010; Tracy, 2016). We sought to work within that culture to identify and promote systems-level processes that maximised women's autonomy. As a result, refinements to the MCP process have already been made at the study site (such as making women aware of their MCPs and providing each woman with a copy of it) and clinicians and consumers in other settings have indicated interest in adapting the process for their own contexts. Additional work remains: On the basis of lessons learned in the current study, we plan to develop a more comprehensive process for accommodating refusal of recommended maternity care that both respects women's autonomy and supports clinicians. We then hope to investigate the utility of that process in a prospective study conducted in a range of maternity care settings. The design and conduct of that proposed future research will require a similarly strategic approach if it is to secure greater respect for women's autonomy in maternity care. We term our approach "Agenda-driven research" (see Table 6).

Table 6: Agenda-driven Research.

1. Identify a research agenda, in collaboration with the community of concern, including expanding the intended audiences of research to include those in empowered change-enabling positions.
2. Strategically choose theoretical lens/s suitable for engaging intended audiences.
3. Develop research questions that maximise the likelihood of engagement of intended audiences and underpin the transformative agenda.
4. In the literature review: include discussion of diversity and oppression, and systems-level processes that might support change.
5. Use labels that are both empowering to participants and familiar to intended audiences.
6. Collect data that is valued by intended audiences and plan analyses that reflect a multi-layered and complex account of participants' experiences.
7. Plan for negotiation and awareness-raising about the nature, role, value and limitations of both quantitative and qualitative data and methods.
8. Adopt a nuanced approached to examining power relationships in ways that support the engagement of intended audiences.
9. Use results to support recommendations for policy and practice.

Agenda-driven Research

Agenda-driven Research is a transformative approach to HSR (see Figure 9). It has some similarities and significant differences with other participatory methods such as Participatory Action Research (Kemmis *et al.*, 2013), Community-based Participatory Research (Wallerstein & Duran, 2010) and Experience-based Co-design (Donetto *et al.*, 2014). The focus of these participatory approaches is on the engagement of health consumers, and often more specifically on “empower[ing] participants to take control of the political and economic forces that shape their lives (Healy, 2001, p. 3). However, in healthcare, empowering patients may not be sufficient to improve the quality of their interactions with clinicians. For example, a systematic literature review of studies which have examined the use of Question Prompt lists (QPLs) to encourage patient-involvement in shared-decision making found that whether the doctor actively endorsed the use of the QPL was a deciding factor in the effectiveness of the approach (Sansoni *et al.*, 2014). Likewise, writing a birth plan is often favoured by women as a strategy to communicate their birth intentions to clinicians, but studies have concluded that they may not help women avoid unwanted intervention and may even provoke negative responses from clinicians (Lothian, 2006; White-Corey, 2013). Thus the focus of participatory methods on empowering “oppressed groups to become actors in a creative process rather than targets of intervention” (Finn, 1994) may not be sufficiently strategic to influence situations where change is needed at a systems level (Healy, 2001).

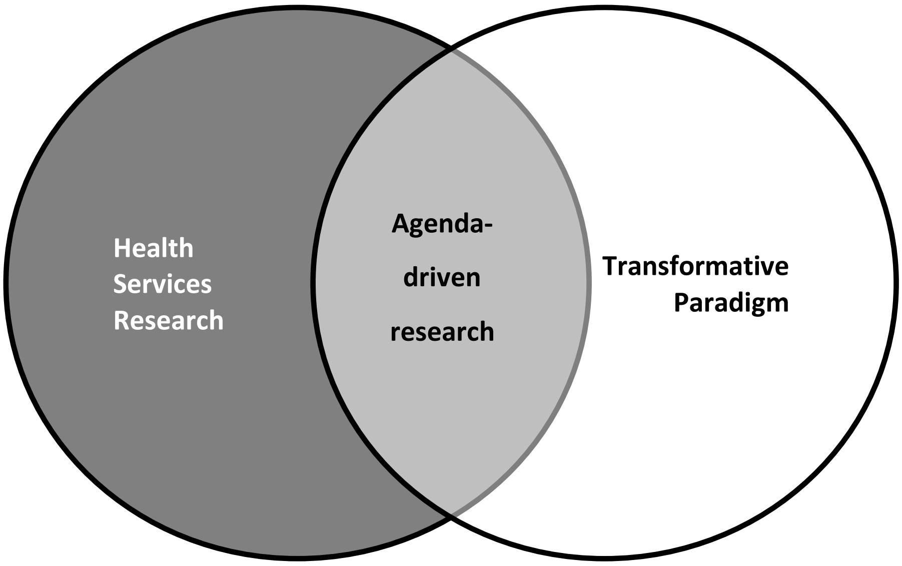


Figure 9: Agenda-driven research is a transformative approach to health services research

Embracing participatory methods may also have significant consequences for individuals whose credibility as researchers is contested. Healy (2001, p. 9) acknowledges this in the context of social work: “It is one thing to give up the status of scientific investigator, as some researchers have done, to pursue [Participatory Action Research]; it is a much more risky thing to do if one was never regarded as a researcher”. Arguably, a similar issue impacts upon maternity consumer and midwife researchers. Action research approaches have been strongly criticised in the health research (Robert, 2013a), making any decision to adhere to other, relatively uncontested, methods understandable.

Nonetheless Agenda-driven Research is a participatory method; this study was led by a maternity consumer undertaking doctoral study. Health consumer involvement remains relatively rare, especially in maternity (Cheyne *et al.*, 2012), despite strong policy support more broadly (National Health and Medical Research Council & Consumers Health Forum of Australia, 2016). Efforts to redress this mismatch have yielded more inclusive ways of generating and prioritising research questions (Cheyne *et al.*, 2012; James Lind Alliance, 2017). Agenda-driven research builds on this by describing a strategically participatory approach to conducting health services research in order to influence practice and therefore, indirectly, women's experiences of care.

Like Agenda-drive research, Experience-based Co-design seeks to bring together clinicians and health consumers to improve the quality of care (Donetto *et al.*, 2015). Nonetheless, a recent review of Experience-based Co-design studies found that such studies continue to report challenges with engaging clinicians and with the "reconfiguration of the relationships of power between citizens and public services" (Donetto *et al.*, 2015, p. 228). It is with this in mind that the purpose and focus of the participatory aspects of Agenda-driven research are not necessarily with the empowerment of the community of concern. Instead, the focus is on strategically engaging those in change-enabling positions (in this case: study site senior managers, obstetric and midwifery leaders) for the purpose of engagement and uptake, rather than empowerment.

Health Services Research has thus far had only limited success in influencing policy and systems-level change (Gilson *et al.*, 2011). While the transformative paradigm provides a useful framework within which to conduct activism-oriented research, established criteria for transformative research may be difficult to apply to the HSR context. Agenda-driven Research bridges this gap. The cornerstone of Agenda-driven Research is identifying the intended audience of the research, the "comfortable men", or those who are in empowered change-enabling positions. Engaging those audiences relies on designing and conducting research in ways that ensure 'buy-in' to the topic, maximising the likelihood that access is gained for research and that recommendations arising from a study will be viewed as credible and adopted. Agenda-driven Research expands on established criteria for transformative research to provide a methodological framework useful for those interested in using research to driven woman-centred reform in maternity services, and more broadly, patient-centred reform in healthcare. Arguably this approach may also be applicable in other fields as well, where the power to create change lies outside the community of concern.

Conclusion

In the absence of suitable methodological frameworks to underpin the activist orientation of our research, we have described and sought to legitimise Agenda-driven Research. Although adopting an activist-orientation in HSR may be controversial (Cairney & Oliver, 2017), even research which maintains the façade of neutrality and objectivity has an agenda, albeit often not explicitly (Lupton, 1997). By describing and legitimising Agenda-driven Research, we seek to create space for researchers to acknowledge, and reflect on their agendas. Indeed, we argue that having an agenda in research is both inevitable and strategically useful: Agenda-driven research situates and legitimises activism-oriented HSR within the broader transformative paradigm.

Chapter Eight: Using the master’s tools to dismantle the master’s house

Introduction[9]

This study set out to support women’s rights to refuse recommended maternity care by promoting the need for systems-level responses. The research question, *Could a documentation and communication process support pregnant women’s rights to decline recommended maternity care?*, was investigated through a sequential mixed methods study. The quantitative phase, a retrospective review of cases documented via the Maternity Care Plan (MCP) process (see Chapter Four), led to the recruitment of women, midwives and obstetricians for the qualitative phase. The qualitative phase involved semi-structured in-depth interviews about participants’ experiences of refusal of recommended maternity care (see Chapters Five and Six). However, the preceding chapters demonstrate that although the MCP process reassured obstetricians and the health service about their own medico-legal and reputational exposure, and thus indirectly supported women’s access to care, the larger forces of patriarchy and medical hegemony continued to undermine women’s autonomy. This study has not sought to disentangle the relative influences of patriarchy and medical dominance, but has concluded that declining recommended care transgressed norms associated with both medical dominance and the patriarchal institution of motherhood, leading to the use a range of intrusive strategies intended to get women to comply with recommended care. This study also documented an apparent gap between clinicians’ espoused and reported practices, termed here the “clinician’s line in the sand.”

In designing and conducting this study, I also found that the strategic approach needed to pursue the overarching activist aim of this research could not easily be fitted within existing research frameworks. While situations of maternal refusal are gendered and power-laden, there are already numerous analyses documenting power imbalances in medicalised maternity care. The goal of this study was not to document those issues in the specific context of refusal, but to actively promote respect for women’s rights to refuse by finding ways to work *within* the gendered and power-laden reality of maternity care. This thesis therefore also serves as an illustration (discussed in detail in Chapter Seven) of an activism-oriented approach to Health Services Research: Agenda-driven research.

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[9] Sections of this chapter have also been redeveloped into a paper for publication entitled “Refusal of recommended maternity care: Time for a pact with women?” That paper is currently under review.

Thus, in answer to my research question, it appears that although the MCP process was only partially successful in supporting women's rights to refuse recommended care, there were benefits arising from a structured documentation and communication process. This chapter now concludes this thesis by addressing the fifth research objective: to outline recommendations for policy, practice, education and research that could support respectful maternity care when women decline to follow professional advice. These recommendations were devised to operate within the context of medicalised Australian hospital maternity care.

The reality of maternity care in Australia

In Australia, as in other high resource settings, medical dominance over childbirth is far reaching and accompanied by high rates of unnecessary intervention (Miller *et al.*, 2016). Although contemporary obstetrics claims to have largely saved women from the threat of death in childbirth, the benefits of medicalisation have often been contradictory and overstated. Such claims, however, continue to nurture a passive and dependent populace (Cahill, 2001; Fahy, 2007; Murphy-Lawless, 1998). Although woman-centred care has become a cornerstone of progressive healthcare policy, "there seems to be a point at which the value of foetal [sic] life begins to outweigh, perhaps not so much the life of the mother, but perhaps her right to self determination, her plans and her choices" (Cahill, 2001, p. 340).

Although medical control of childbirth is promoted as being about the safety of women and babies, it is a gender-based oppression (Cahill, 2001; Diaz-Tello, 2016a). Historically, medical domination of childbirth created a link between the autonomy of birthing women and the autonomy of midwives (Cahill, 2001; Edwards & Murphy-Lawless, 2006; Murphy-Lawless, 1998). Gendered commercial interests constructed a safety agenda that was premised on and promoted a belief in the incompetence and unreliability of women, whether to birth babies or to be midwives (Cahill, 2001; Murphy-Lawless, 1998; Rich, 1995). In Australia, the subordination of midwifery and the medicalisation of childbirth followed a pattern similar to that in Europe, but with the addition of a strategic alliance between medicine and nursing that served these groups' vested interests to exclude midwifery (Fahy, 2007).

Until recently, medical dominance in Australia has been sustained by our parallel systems of public and private healthcare provision. Medicare, Australia's public health insurance system, has been at the heart of state-supported medical dominance since its inception in 1984. Simultaneously, "government advocacy for [private hospital insurance] and little support for primary maternity health care has cemented obstetricians' dominance and increased the medicalisation of childbirth" (Benoit *et al.*, 2010, p. 478). Nonetheless, social changes, such as access to education for women, have diminished the privilege that sustained medical dominance (Fahy, 2007). A "synergy of interests" (Fahy, 2007, p. 29) has emerged between women and midwives (both interested in normal birth and midwifery models of care) and Australian governments (interested in containing the spiralling costs of healthcare), at a time where the evidence base that supports midwifery models of care could not be stronger (McLachlan *et al.*, 2012; Sandall *et al.*, 2016; Tracy *et al.*, 2013). Australia-wide, state governments have sought to expand midwifery models of care (Australian Health Ministers' Conference, 2010), as they have in the United Kingdom (UK; Cumberlege, 2016). In 2010, the Australian government extended Medicare to cover some midwifery services (Department of Human Services, 2014), eroding the "very substantial competitive advantage that the medical profession holds vis-à-vis the services of other health care professionals" (Benoit *et al.*, 2010, p. 426). Perhaps unsurprisingly moves towards increasing women's access to midwifery-led care have been met with sustained medical opposition, restricting the establishment, full implementation and sustainability of such models of care (Kruske *et al.*, 2016).

The latest incarnation of sustained opposition saw the Australian Medical Association (AMA, 2016) campaigning against midwifery models of care. Largely played out in sensational media (Tracy, 2016), the AMA raised safety concerns on the basis of a single retrospective cohort study (Wernham *et al.*, 2016), despite calls for more cautious interpretation of that study (de Jonge & Sandall, 2016; Tracy, 2016). The AMA's campaign was also not tempered by a Cochrane review of randomised controlled trials of midwifery-led care that supported the safety and quality of these models of care (Sandall *et al.*, 2016) with many of the original trials conducted in Australia. Their actions were characteristic of the "politically skilful … rear guard action" that medicine deploys to sustain its dominance (Willis, 2006, p. 423). Contemporary obstetrics sets out, as it did at its dawning, to "deliberately… frighten women… by exaggerating the dangers of childbirth" in order to gird up an obstetric monopoly (Cahill, 2001, p. 338).

This is the context in which women may seek to decline recommended care, and in which any effort to support women's rights must be situated. The recent AMA campaign against midwifery models of care makes it readily apparent that evidence is not enough. Yet efforts towards reform must recognise that the "engine of change" in maternity services is "the determination of people at the front-lines of health systems—patients, providers, and managers" (Freedman, 2016, p. 2069). With that in mind, demonising and alienating obstetricians is only counter-productive, as is ignoring the very real ethical, moral and medico-legal fears they grapple with when women decline recommended care. A more strategic approach is needed, making use of the 'master's tools' to enable woman-centred, respectful maternity care for women who decline recommended care.

The master's tools

Audre Lorde famously argued that the

> "the master's tools will never dismantle the master's house. They may allow us temporarily to beat him at his own game, but they will never enable us to bring about genuine change" (Lorde, 1983, para 9).

In its original context, Lorde, a radical feminist, argued that merely adding women to patriarchal structures would not transform them, much as growing numbers of female obstetricians have not radically shifted the patriarchal culture of obstetrics (Murphy-Black, 1995). Medicalised maternity care, which feminist and midwifery scholars have a long history of critiquing (see Crossley, 2007; Davis-Floyd, 2008; Donnison, 1988; Katz Rothman, 1989; Keating & Fleming, 2009; Kirkham, 2004b; Murphy-Lawless, 1998; Newnham, 2014; O'Reilly *et al.*, 2005; Oakley, 1984; Rich, 1995; van Teijlingen *et al.*, 1999), remains one such patriarchal structure. That is, medicalised maternity care is a 'master's house' within which women's autonomy is conditional upon their compliance with norms of patienthood and motherhood. Likewise, the MCP process investigated in this study can be conceptualised as one of the master's tools since it served mainly to reassure obstetricians about their own medico-legal and professional exposure.

Robin James (2009) argues, however, that we should not so quickly dismiss the master's tools nor underestimate the benefits that may accrue from their use. Indeed, providing they are "appropriately hacked," the master's tools may be very useful for achieving feminist goals (James, 2009, p. 78). Successful reappropriation of the master's tools relies on two conditions: firstly, that "nothing else does quite what the master's tools do" and secondly, that "the very process of an 'outsider's' appropriation of 'insider' privilege collapses the insider/outsider or master/marginalized distinction, so the procedure is itself transformative" (James, 2009, p. 78). The following sections draw on James' notion of reappropriating the master's tools to outline a comprehensive system-level approach for promoting respect for women's rights to decline recommended maternity care.

Policy

Australian health policy foregrounds woman-centredness, including in the *National Maternity Services Plan* which described a five-year vision that "maternity care will be woman-centred, reflecting the needs of each woman within a safe and sustainable quality system" (Australian Health Ministers' Conference, 2010, p. 3). Indeed patient-centredness (as it is known in other areas of healthcare) is widely recognised as a dimension of quality in healthcare (Black, 2009; Institute of Medicine (US), 2001), and in maternity care at least, that has included calls to look beyond mortality and morbidity, towards values and dignity (Freedman & Kruk, 2014; Prochaska, 2015). In other areas of health care, such as palliative care, the place of patient autonomy is foregrounded and process is valued as an outcome in itself (Tilden *et al.*, 2017). Some authors therefore suggest that despite the differences between these two areas, maternity care would do well to borrow from palliative care frameworks in order to "more objectively value patient autonomy and … acknowledge the emotional, spiritual, and social aspects of birth" (Tilden *et al.*, 2017, p. 9).

Before it expired in 2015, the *National Maternity Services Plan* (Australian Health Ministers' Conference, 2010) underpinned significant woman-centred reform in Australian maternity services. However, it failed to specifically address women's rights to refuse recommended care. Indeed, the White Ribbon Alliance's (WRA, 2011) charter on *Respectful Maternity Care: The Universal Rights of Childbearing Women* has gained little traction in Australia. This may be because, until recently, Respectful Maternity Care was perceived as an issue only in low-resource settings. Increasingly, however, awareness is growing that the over-medicalisation prevalent in high resource settings, is equally an issue of disrespect and abuse (Miller *et al.*, 2016). These issues remain unaddressed in the next iteration of Australian maternity policy, the *National Framework for Maternity Services* which seeks to establish an enduring vision for maternity service across the nation (COAG Health Council, 2017). The draft of this Framework was recently abandoned, following broad criticism from all stakeholder groups (medical, midwifery and consumer), including for the lack of emphasis it accorded to physiological birth or to a woman's role as the decision maker about her maternity care. High-level policy is urgently needed in Australia to reaffirm women's rights to refuse recommended care, and to protect their unconditional access to hospital maternity care irrespective of their birth intentions.

Women in this study were often tentative about their right to refuse recommended care, concerned about being refused care at the hospital and unaware of the MCP process and its purpose. Numerous other studies have likewise found that women are concerned about their autonomy in childbirth

(Edwards, 2005; Jackson *et al.*, 2012; Kornelsen & Grzybowski, 2012; Rigg *et al.*, 2015) and reluctant to be seen as difficult (Campo, 2010; Dixon-Woods *et al.*, 2006; Ebert *et al.*, 2014; Edwards, 2004). Broad awareness raising about the policy development recommended here would help make women more aware of their right to decline recommended care (along with their other healthcare rights). It would empower women to participate more actively in decision-making and indirectly support equity, since "educated, energetic patients are more likely to find … things out independently than disadvantaged patients" (Williamson, 2005, p. 1079).

Recommendation 1: Develop and raise awareness about systems-level policy that adopts Respectful Maternity Care as a framework to affirm women's rights to refuse recommended care, and protects their unconditional access to care irrespective of their birth intentions.

Practice

Following on from policy that promotes women's autonomy and rights in maternity care, supportive mechanisms are needed to promote the practice of respectful maternity care. This study identified a gap between clinicians' espoused practice and the experiences of women. Like other studies before it (Biscoe & Kidson-Gerber, 2015; Brass, 2012; Dann, 2007; Hall *et al.*, 2012; Iris *et al.*, 2009; Kruske *et al.*, 2013; Perry *et al.*, 2002; Ribak *et al.*, 2011; Weiniger *et al.*, 2006), this study identified that situations of maternal refusal are stressful for both midwives and obstetricians. This likely contributed to their use of intrusive strategies to get women to comply and suggests that clinicians (and therefore women, indirectly) would benefit from support during and after such episodes of care.

Although the MCP process did not appear to entirely prevent intrusive care interactions following a woman's refusal of recommended care, the reassurance it appeared to offer may have expanded the situations in which clinicians were willing to provide care. Maternity Care Plans were authored by obstetricians and endowed women's birth preferences with a perception of being 'authorised.' This perceived obstetric authorisation benefited the woman because it reassured subsequent clinicians involved in her care, and the health service, about their own medico-legal, reputational and professional exposure. While women may (rightly) not share the view that they need 'permission' to decline recommended care (Pascucci, 2014b), clinicians working in hierarchical hospital settings may well perceive that *they* do need permission to deviate from local policies. Numerous other studies also have called for additional guidance for clinicians navigating maternal refusal (Chigbu & Iloabachie, 2007; Cuttini *et al.*, 2006; de Crespigny & Savulescu, 2014; Ireland *et al.*, 2011;

Kruske *et al.*, 2013), advocated for timely counselling of women (Perry *et al.*, 2002; Weiniger *et al.*, 2006), and a harm minimisation approach (Ecker & Minkoff, 2011, p. 1182). Without clear local policy affirming women's rights to refuse recommended care, and robust documentation and communication processes affording medico-legal protection to the health service and its employees, clinicians may be realistic in their expectation of (at least) professional censure should their practice deviate from local policies.

Returning then to James' (2009) argument that the master's tools can be appropriately hacked for feminist ends, she argues that since "all agency arises from one's insertion in networks of power relations, then one must be 'recognizable' to the 'master's' system(s) in order to participate in the working(s) of power in the first place" (James, 2009, p. 84). Structured documentation and communication processes like the MCP can participate in the workings of power within a hospital in ways that women's birth plans, or women themselves for that matter, do not. In medically dominated, hierarchical hospital settings, they can also participate in the workings of power in ways that midwives and registrars do not. That is, a structured documentation and communication process may be one of the Master's tools, but "nothing else does quite what the master's tools do." Nonetheless, this study identified a range of shortcomings of the MCP process and barriers to its use. While the features of the MCP process that enabled it to function within a medically-dominated maternity setting should be retained (such as obstetric assent), a greater emphasis on woman-centeredness is needed both within the documentation and communication process and within the broader context in which care is provided.

The PACT process

The MCP process supported women's right to decline recommended care by providing an assurance of ongoing access to care (see Chapters Four and Five), however it was used for a very limited number of conditions and excluded women from the process. In addition senior managers, doctors and midwives intellectually supported women's rights to decline recommended care but seemed unaware that this was subject to their own value system of what was acceptable (see Chapter Six). Drawing on these findings, a broader and more woman focused framework was developed that could still be acceptable to be decision makers or 'masters' of maternity care (senior doctors). This framework is termed the PACT process (**P**ersonalised **A**lternative **C**are and **T**reatment process; see Figure 10), and it may address the limitations of the MCP process in ways that satisfy James' (2009) criteria for a successful reappropriation of the master's tools. Importantly, the PACT process

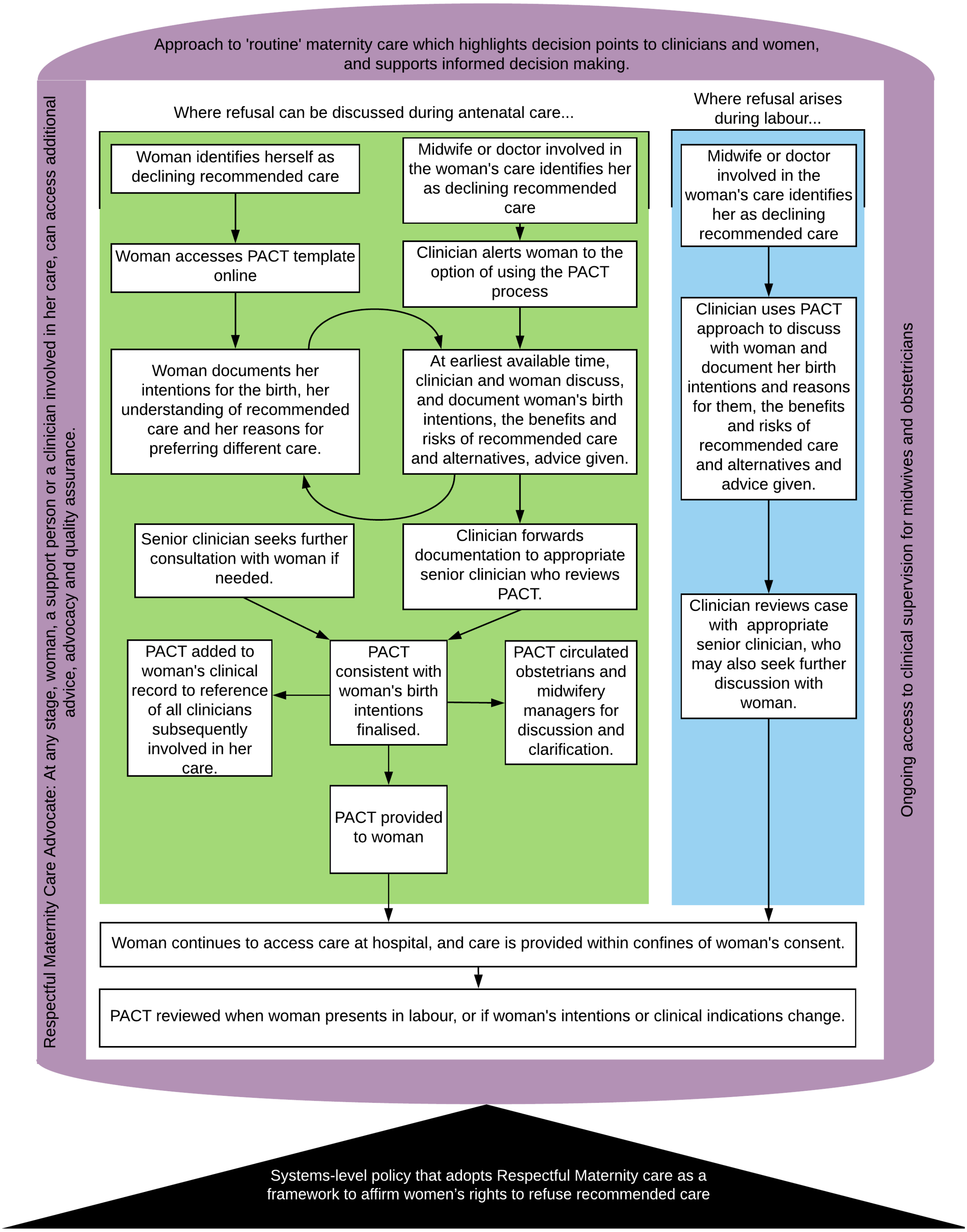

Figure 10: The Personalised Alternative Care and Treatment (PACT) Process

sits on the policy foundations discussed in the previous section and retains a structured approach to documentation and communication, similar to that seen in the MCP process. However, the PACT process prioritises *exchanging* of information with women, and particularly the inclusion of the woman's voice in documentation. It also offers more flexible initiation pathways and is designed to yield a 'living' plan. The entire process is nested within the context of ongoing access to clinical supervision for obstetricians and midwives. Ideally, the process would be under the aegis of a health jurisdiction rather than being specific to a model of care or individual health service.

Exchanging information with women

The PACT framework enables information to be exchanged between women and clinicians in order to inform the co-development of a plan for maternity care within the confines of her consent. This plan is structured within a template, in order to scaffold more sensitive discussions with women, and more thorough documentation (as discussed in Chapter Four). Other studies have similarly concluded that improving communication between women and care providers would address women's feelings of loss of control and being excluded from decision making (Baker, 2005). The content of this template, however, foregrounds the importance of eliciting the woman's perspective (see Appendix D).

Clinicians can ensure their communication with women is clear and ethical by observing the distinction between *offering* and *recommending* a course of action (Kotaska, 2017), and the distinction between acceptable and unacceptable forms of persuasion (Shaw & Elger, 2013). Shaw and Elger (2013) identify three different types of persuasion, only the first of which is always appropriate: the removal of biases, recommending a particular course of action and providing evidence and reasons in favour of it, and the creation of new biases. The latter of these, involving for example the manipulation of information to overstate benefit or understate risk, is "unacceptable" (Shaw & Elger, 2013, p.1689).

The exchange of information in the PACT process would see clinicians give advice to women in ways which clarify the gravity of a woman's refusal. By communicating appropriate, unbiased information about the risks and benefits of *both* recommended care and the woman's intended course of action, clinicians can address any misconceptions or knowledge gaps, and avoid creating new biases. Where there is clear evidence in favour of a particular course, where the benefits clearly outweigh the risks, clinicians are justified in recommending that course (Kotaska, 2017). Where the evidence is equivocal or difficult to apply to the woman's unique individual circumstances or where the clinician judges the risks and benefits to be of similar weight, then more tentative advice is appropriate: offering, rather than recommending (Kotaska, 2017). This balanced approach may be challenging to deliver, especially in the context of maternity care (Minkoff & Marshall, 2016), and should therefore also be the focus on continuing education for clinicians (discussed further below).

Exchanging information in the PACT process also extends to purposefully eliciting the woman's perspective. The information elicited from (and documented by) a woman would include her reasons for declining recommended care, what her intended course of action is, and her understanding of advice and information given to her by clinicians and located from other sources. Chapter Five highlighted the omission from MCP documentation of women's reasons for refusing recommended care, despite some obstetricians describing this as central to their counselling. In particular, in Chapter Six, understanding the woman's perspective was identified as a key component of supportive care interactions that were reportedly valued by both women and clinicians. Such understanding has also been identified in other studies as enabling clinicians to maintain respectful care practices (Minkoff & Paltrow, 2007, p. 316; Scott, 2007). It also responds to the maternity consumer movement's long standing demands for care providers to listen more closely to women's knowledge, experiences and anxieties (Edwards & Murphy-Lawless, 2006).

When declining recommended care, women grapple with "competing interests, influences and social pressures" (Laufer-Ukeles, 2011, p. 614). Understanding this may enable clinicians to "relinquish the locus of control and reassure a patient [sic] that she will continue to be cared for after her refusal [which] … dissolves tension and strengthens the therapeutic alliance" (Kotaska, 2017, p. 4). It also makes visible, prioritises and protects "relationships between women and babies and within the family" (Edwards & Murphy-Lawless, 2006, p. 44). Too often, the importance women give to these relationships is overlooked by obstetric ideology, creating an erroneous perception that women who decline recommended maternity care are pursuing a particular experience 'at any cost' (Edwards & Murphy-Lawless, 2006).

Another example of documentation which directly includes the woman's voice is found in the Australian College of Midwives' (2014) Record of Understanding where parallel sections are completed by the woman and clinician (in that case, midwife). That approach was considered, but rejected in favour of the PACT template (see Appendix D) because the ACM's Record of Shared Understanding may be perceived as mainly relevant to midwives and inapplicable to doctors. Even amongst midwives, it may be perceived as being most relevant to privately practicing midwives. Nonetheless, aspects of the ACM Record of Shared understanding accord with the findings of this study and have been adapted for the PACT template.

For example, both approaches reflect three stages: discussion/advice; development of a plan; and declarations co-signed by the woman and clinician. The co-development of documentation is evident in both approaches, although the woman's and clinician's contributions are arranged sequentially in the PACT template, rather than side-by-side. Although both approaches call for clinician's to document the advice they have given to women, in the PACT template, this is broken down more finely in order to scaffold the inclusion of advice about the maternal and fetal benefits and risks associated with recommended care and the woman's intended birth. The decision to build in more scaffolding to the PACT template was taken due to the finding that women valued a balanced approach to the discussion of risk, but perceived this had been lacking form their care (as discussed in Chapter Six and above).

Both the ACM approach and the PACT template also foreground the importance of clinicians consulting with colleagues and developing a plan for the woman's ongoing maternity care. The PACT template adds the element of obstetric review of the documentation, which is a strategy for ensuring that the PACT process functions within a hierarchical medicalised maternity care setting. The risk of this step being perceived as 'permission giving' is offset against the assurance of continued access to care. Indeed continued access to care is a final important difference between the declaration steps in the PACT template and the ACM Record of Shared Understanding. The ACM Record of Shared Understanding incorporates the option of the midwife withdrawing from the care of a woman, whereas the PACT template does not. The PACT template is intended to function at a health service level, rather than at the level of an individual clinician, meaning that while an individual clinician may regard the woman's care as beyond their scope of practice, the health service itself would not refuse the woman access to care. This is a fundamental aspect of the PACT process and consistent with a harm minimisation approach. These features of the PACT process and template are discussed further in the following sections.

More flexible initiation pathways

A woman-centred approach also sees a wider variety of stakeholders empowered to initiate the PACT process. As discussed in Chapter Five, the benefits of obstetric authorisation particularly accrued to junior doctors and midwives who felt protected from professional censure, yet these clinicians were unable to initiate MCPs directly and were unsure when an MCP was warranted. With this in mind, the PACT process embeds flexibility with regard to when, and by whom, it is initiated. Enabling both women and clinicians to initiate the PACT process could counterbalance the clinician-centred criteria that appeared to limit the accessibility of the MCP process (as discussed in Chapter Five).

The benefits of the MCP process were also limited by the late stage of pregnancy at which MCPs were created. As discussed in Chapter Five, this meant that MCPs could not play a role in limiting the woman's exposure to repeated rounds of counselling about risk, which women and midwives perceived to be badgering. A PACT could, therefore, be initiated whenever the women signalled her intention to decline recommended care. In some cases, this would also allow proactive steps to be planned and undertaken antenatally to maximise the chances of good outcomes, such as in the care of women who decline blood products (see Belaouchi *et al.*, 2016; Kidson-Gerber *et al.*, 2016; Queensland Maternal and Perinatal Quality Council, 2012). As discussed in Chapter Four, some women may signal their intention to decline recommended care as early as their booking visit. For others, such as those with breech presenting babies or post-term pregnancies, a decision to decline recommended care may not arise until much later in pregnancy. The PACT process has the necessary flexibility to accommodate these variations.

However, on some occasions women may not articulate a refusal until after they are in labour. This may be because an aspect of care that the woman prefers to avoid is not recommended until that time. In this case, it may not be possible or appropriate to undertake the PACT process in its entirety. However, a version of the PACT process can still be used to guide communication, elicit the woman's perspective, seek support from colleagues and enhance the quality of documentation. This condensed version of the PACT process is depicted through the 'in labour' pathway of Figure 10.

A 'living' plan

Whenever it is created, the PACT documentation would then be reviewed by a consultant obstetrician (or other senior clinician, depending on the model of care), who may seek further consultation with the woman, before finalising the PACT and circulating it to obstetric staff, midwifery managers and the woman. Similar circulation of the documentation was valued by clinicians in this study, and has several benefits. Firstly, it enables all clinician's to be informed about the woman's circumstances and decisions, which may help establish a respectful atmosphere in future clinical encounters and prevent the woman from having to 'tell her story' repeatedly (Zeybek *et al.*, 2016). It would also provide an opportunity for constructive and critical debate amongst clinicians, which is respectful of each clinician's own autonomy, while still protecting the woman’s access to care at the hospital. Clinicians in this study also reported feeling reassured by sharing their decisions and inviting commentary from their peers. Some also perceived that this sharing had helped improve the quality of documentation over time.

The woman’s PACT plan is then intended to be a ‘living’ document. That is, it can be reviewed at the onset of labour or if the woman’s intentions or clinical indications change. The vast majority (all?) of women who decline recommended maternity care are not seeking one particular birth experience at the expense of (physical) safety (Downe, 2015; Edwards & Murphy-Lawless, 2006). Rather, they may seek to discuss alternatives or wish to develop a ‘if, then’ plan to accept intervention only if their own clinical circumstances, during their pregnancy, labour or birth, indicate that intervention is needed. This kind of responsiveness to changing indications serves as a safety net, and is therefore a key component of the PACT process.

Recommendation 2: Establish the PACT process under a systems-level aegis to support documentation and communication when women decline recommended care.

Time to make a PACT?

The PACT process represents radical reorientation of the MCP process that, I believe, could meet the needs of all participants in maternity care: women, midwives and doctors. By assuring women of access to care (not currently the case in practice in Australia), and focussing on exchanging information with women (rather than expert to woman transmission of risk information only), women could reappropriate the MCP process to satisfy their own priorities. Retaining obstetric assent ensures that the process continues to function in medically dominated hierarchical maternity care settings in order to address the professional and medico-legal fears that led to the use of intrusive strategies documented in this study. Nonetheless, I acknowledge that participating in a structured documentation and communication process represents a trade-off for women between their unambiguous right to refuse recommended care and the risk of being labelled as deviant. I believe this trade-off is necessary in Australian maternity care in order to protect women’s access to care; that is, a structured documentation and communication process which risks a woman being labelled as deviant may be better than not having such a process and risking a woman being denied access to maternity care.

A broad range of women’s choices may fall under the banner of ‘declining recommended care’ and the likelihood of provoking negative responses from clinicians may vary depending on characteristics of the woman and the clinician providing the care (as discussed in Chapter Six, see also Samuels *et al.*, 2007). With this in mind, there are also several specific situations where the PACT process may be of particular benefit. These include when women decline aspects of care regarded as routine, prefer vaginal birth after previous caesareans (VBAC), prefer to birth in their rural or remote community or in their chosen model of care despite not meeting exclusion criteria, or where they prefer care that is not yet widely available. The following sub-sections describe how the PACT process could be useful in each of these situations.

Making a PACT about routine aspects of care

In the current study, MCPs were rarely created when women declined routine aspects of care, such as vaginal examinations or continuous electronic fetal monitoring in an otherwise normal labour and birth. In practice, these interventions may often be presented as routine care and women may not realise that they have the option to refuse them (Declercq *et al.*, 2013; Lewin *et al.*, 2005; Thompson & Miller, 2014). Supporting women's autonomy in maternity care, therefore, requires an overall approach that highlights decision points that may be concealed by the routinisation of care (represented in the surrounds of Figure 10). Once these decision points are recognised, the risks and benefits of routine interventions and their alternatives can be discussed. The goal of these discussions is agreeing on a course of action, but respect for women's autonomy means that that agreement may not always be reached. For clinicians, however, compliance with evidence-based clinical guidelines is increasingly regarded as protection from blame and litigation (MacKenzie Bryers & van Teijlingen, 2010), so much so that it can restrict women's and clinicians' autonomy and supersede ideals of woman-centredness (Klein *et al.*, 2007; Kotaska, 2011a; Scamell, 2014). Both this and other studies have found that deviating from policies and guidelines to provide woman-centred care is regarded by clinicians as likely to (at least) attract censure from colleagues (Hall *et al.*, 2012; Thompson, 2013). This has led to calls for a "quantum leap" in both the content and application of clinical guidelines in order to prioritise women's autonomy. The PACT process could underpin such a leap, by providing a governance framework within which women's rights to refuse recommended care were affirmed and supporting clinicians to discuss, document and ultimately provide care that might deviate from 'routine practice' in order to meet women's needs.

Making a PACT about access to care for VBACs

Many of the MCPs in this study were created for situations relating to vaginal birth after CS (VBAC), which is one aspect of care on which midwives may have more supportive responses than obstetricians (Appleton *et al.*, 2000; Reime *et al.*, 2004). Even within obstetrics, opinions about the relative merits of VBAC and elective repeat caesarean section differ widely (Shorten *et al.*, 2005). Despite long-standing clinical guidelines recommending VBAC in ‘low risk’ women with one prior caesarean section (CS; American College of Obstetricians and Gynecologists (ACOG), 2010), access to VBAC care is declining (Charles, 2012) and women face considerable pressure to accept repeat CS (Goodall *et al.*, 2009; McGrath *et al.*, 2010; Munro *et al.*, 2016).

In many places, local policies ‘prohibiting’ VBAC undermine women’s autonomy (Kotaska, 2007; Munro *et al.*, 2016; Pratt, 2013) and are typical of the contemporary pattern of allowing fetal risks to figure more prominently in policy-making than risks to women. Kotaska argues that “anyone advising a woman to have a cesarean delivery [sic] to avoid a 1/2000 fetal risk from uterine rupture should pause to reflect that the risk of maternal death with elective caesarean … [is] 1/2400” (Kotaska, 2017). That is, the risk to the woman of a repeat CS is similar to the risk to the fetus in a VBAC, yet repeat CS is widely accepted, even mandated. This is part of a wider pattern of focussing on immediate fetal outcomes, at the expense of maternal and long term outcomes (D'alton, 2010; Martin & Montagne, 2017) and women’s experiences (Cahill, 2001; Edwards & Murphy-Lawless, 2006; Wendland, 2007). Policies restricting access to care for VBACs also represent a conflict of interest for clinicians when their ethical obligations to the woman and their contractual obligations to their employer collide (Charles, 2012).

While VBAC remains relatively widely available in urban Australian settings, women with multiple prior CS may have more difficulty accessing care; several women in this study had been denied care under those circumstances. Given that the risks of repeat CS rise with each additional CS (Cook *et al.*, 2013; Ozcan *et al.*, 2015), these women may well have been motivated at least in part by concerns about biomedical risk. Nonetheless, the preceding chapters have deliberately avoided detailed discussion of whether particular birth intentions were ‘evidence-based’ or ‘risky’ in a biomedical sense. In many ways, it doesn’t matter; the right to decline recommended care is not attenuated by the likelihood of poor outcomes. This does not diminish, at all, the importance of the meaningful discussion of risk with women, but it does mean that women with multiple prior CS are just as entitled to decline further CS as those with other clinical circumstances.

Studies on the constraints on women’s decisions making about birth after previous CS have called for strategies to address barriers perceived by care providers and policy makers, including the need to manage perceived medico-legal risks (Munro *et al.*, 2016). The PACT process may be one way of managing these risks while protecting women’s access to VBAC services, helping to reverse the tide of repeat CS.

Making a PACT in rural and remote maternity services

Since the 1990s, there has been a marked decline in access to birthing services in rural and remote areas of Australia (Kildea *et al.*, 2015). This means women must travel long distances to await birth in urban centres. While this is regarded as reducing risk by ensuring women birth in tertiary hospitals with immediate access to emergency CS, it also creates different risks which are born by the woman and her family: the social risks of leaving their communities, including financial, emotional, and psychological stress (Kildea, 2006; Kornelsen & Grzybowski, 2012). Travelling longer distances to access maternity care is associated with poorer perinatal outcomes (Grzybowski *et al.*, 2011) and a greater likelihood of birthing en route to the hospital (Kildea *et al.*, 2015).

Some studies have reported relatively high rates of women declining transfer from rural and remote settings to await labour and birth (Ireland *et al.*, 2011). While women cannot ethically be turned away from or safely transferred from a health service if they arrive in advanced labour (colloquially referred to as the '10cm strategy'; see Kornelsen and Gryzbowski, 2012), there are numerous reasons why this is an undesirable approach. Firstly, few women may be willing to adopt such a confrontational approach. Most would reluctantly comply with the requirement to transfer prior to birth. However, the harms arising from unwilling consent (in this case, unwilling consent to transfer) are similar to the harms done by unwillingly accepted sexual intercourse. While analogies between consent in maternity care and rape are always controversial, including in feminist circles (The Feminist Agenda, 2010), the point here is salient: unwilling consent harms dignity (Laufer-Ukeles, 2011). Secondly, the perception that some births are 'not allowed' at a health service may also lead women to avoid antenatal care (Borkan, 2010; Ireland *et al.*, 2011) or engage in "selective telling" (Keedle *et al.*, 2015, p. 1). This prevents an open and rational discussion of the risks of a woman's birth intentions, prevents women from receiving midwifery care during early labour, and prevents health services putting plans in place to meet the woman's needs (Ireland *et al.*, 2011).

In settings where some or all women are advised to birth elsewhere, the PACT process offers a respectful way of discussing, documenting, communicating about and planning the care of women who decline transfer.

Making a PACT in the context of exclusion criteria

Many midwifery models of care also operate with exclusion criteria that impact on women's options for birth. While health services have legitimate aims in establishing exclusion criteria, the blanket application of them without consideration of women's individual circumstances disproportionately impacts on women's rights.(British Institute of Human Rights *et al.*, 2016) This may be especially true for women in now common situations, such as those with previous CS or who have a high body mass index. Women in these situations are often excluded from midwifery models of care, despite being the very women who may benefit most from one-to-one support during pregnancy, labour and birth. Recent studies have also demonstrated the safety of 'all risk' continuity models of care.(Tracy *et al.*, 2013) Exclusion criteria can also indirectly undermine women's autonomy when their continued access to their preferred model of care is made conditional upon consent to certain interventions (such as routine screening for gestational diabetes and ultrasound). The woman-centredness of exclusion criteria are questionable, especially since they reflect "an over-reliance on abstract calculations of risk – far removed from the material lived experience of the mother"(Scamell, 2014, p. 813) This is not to say that it is necessarily appropriate to abandon exclusion criteria entirely and *routinely* offer birth services to all women in all settings. However, the PACT process could be used to support women and clinicians so that women do not lose their preferred model of care when their circumstances see them fall outside of exclusion criteria.

Making a PACT to support changing practice

It is also possible that the structured documentation and communication process examined in this study was useful to clinicians navigating situations that were new to them, or where the evidence-base is contested. For example, clinicians may have initially felt that VBAC2 was 'risky' and therefore warranted robust documentation. Recourse to the MCP process may then have permitted more VBAC2s to occur, which in turn may have seen it become perceived as a more 'routine' option. The PACT process may therefore also be useful in situations where the evidence is contested, such as vaginal breech birth (Kotaska, 2011b), or for securing conditional support for other practices regarded as 'new' or 'untested', such as vaginal seeding (see Cunnington *et al.*, 2016) or waterbirth (still largely unavailable in most Australian hospitals; see Young and Kruske 2012a, 2012b) .

In each of the above situations, the PACT process could support clinicians by providing a structured approach to documentation and communication. One reason that policies restricting women's autonomy (whether to decline CS, or transfer to a higher level setting, or any other refusal) may be considered acceptable is that her birth intentions may be (erroneously) construed as a request, rather than a refusal. This distinction has been emphasised throughout this thesis because it is a significant one, with the latter being an unequivocal matter of negative autonomy. The PACT process offers the opportunity to appropriately recognise the unequivocal nature of a woman's refusal, respect her autonomy and support the clinicians providing care within the confines of her consent. The utility of the PACT process lies in the recognition that while clinicians may justifiably refuse to perform an intervention which they perceive will do more harm than good, "*the provision of care during birth is not an intervention*" (Kotaska, 2017, p. 3, italics in original). Refusing to provide care to a woman is misguided in its bid for safety, since "many, if not most, medical choices will be made safer by a physician's participation" (Ecker & Minkoff, 2011, p. 1179) and "midwifery skills may… provide greater safety than technocratic solutions because they achieve the same outcome but avoid some of the harmful impacts of more invasive technology" (Edwards & Murphy-Lawless, 2006, p. 46).

Recommendation 3: Ensure that all women are aware their right to request a PACT and develop woman-centred criteria for the initiation of a PACT which include: recognition of decision points in routine maternity care; specific support for women planning VBACs, in rural and remote settings, and in models of care with exclusion criteria; and to support emerging practices.

Education & Professional Issues

In the current study, clinicians universally espoused respect for women's autonomy and many obstetricians reported that the MCP process could be used to accommodate any birth intention, regardless of how 'risky' they perceived it to be. However, MCPs were actually utilised for only a very narrow range of situations, and intrusive efforts to get women to comply with recommended care were widely reported. While clinicians espoused respect for women's autonomy, they appeared unaware of the impact of their values and beliefs (particularly about the status of the fetus) and their perceptions of their role as 'expert.' Diaz-Tello (2016a) observed that a similar climate of denial operates around the problems of disrespect and abuse in maternity care in the United States. Improving women's access to respectful care when they decline to follow professional advice must, therefore, be situated in this context: one where clinicians know, at least at an intellectual level, that women have the right to refuse, but where they may not acknowledge or be aware of other influences on their practice.

The PACT process should be underpinned by clinician education and ongoing support for reflective practice, especially to enable clinicians to develop self-awareness about their own 'line in the sand.' Models of clinical supervision are well established in other health professions (eg psychology) but are more often referred to as reflective practice in midwifery (Calvert, 2014). Given that clinicians in this study appeared to have little insight into the existence or impact of their own ‘line in the sand’, participation in clinical supervision should be part of continuing professional development requirements for both midwives and obstetricians.

Having an MCP did not, however, guarantee a woman respectful care, nor entirely protect the clinicians providing her care from criticism and professional censure (see Chapter Five). The results of this study identified that declining recommended care situated the woman at the intersection of medical dominance and the patriarchal institution of motherhood. Perhaps the apparent limitations of MCP process (and probably also the PACT process) to prevent intrusive strategies, was because it addressed clinician’s concerns born out of medical dominance (that is, medico-legal and professional fears), but not those whose genesis was in the patriarchal institution of motherhood: the moral judgement and censure of women who were perceived not to fulfil the powerless responsibility of motherhood. To address this, the PACT process embeds an additional layer of advocacy, termed here the ‘Respectful Maternity Care Advocate’ (RMCA; see Figure 10). The RMCA would be a new role in Australian maternity care that would provide a failsafe[10] that can be activated should conflict arise. The RMCA would provide independent, on-call, real-time support and mediation at any stage of care, even if that be by telephone, to clinicians, women and health services in situations of maternal refusal.

The RMCA is similar to a process known as “Ryan’s Rule,” but with a different focus. In Queensland (Australia), Ryan’s Rule can be invoked when a hospitalised patient (or their parent or carer) is concerned that they are getting worse, not doing as well as expected, or not improving (Queensland Health, 2014). Ryan’s rule was established following the tragic, preventable death of a three-year-old boy in a Queensland hospital after his parents had tried to raise concerns about his deterioration (Queensland Health, 2014). The RMCA role would be similar to Ryan’s Rule, but with a different focus: it would enable a woman, one of her support people or clinicians to call on an independent third-party to provide additional mediation, advocacy and quality assurance to the woman, the clinicians involved in her care and the health service.

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[10] The term failsafe is not intended to imply infallibility. Rather, it means a system that is intended to “counteract the effect of an anticipated possible source of failure” (Merriam-webster.com, 2017, p. 1)

The RMCA role also borrows from the UK's Supervisor of Midwives (SoM) role, which provided (amongst other functions) support to midwives and women when women declined recommended care (Carr, 2008; Read & Wallace, 2014). The establishment of SoMs in Australia was recommended by a recent review of midwifery professional indemnity insurance arrangements in Australia (Price Waterhouse Coopers Australia, 2013), but has yet to gain political support. The term 'supervision' has multiple meanings and a history of surveillance, assessment and misuse of power (Lennox *et al.*, 2008), and therefore the title RMCA is recommended here.

Studies of midwives experiences with supervision in the UK have reported wide variability (Calvert, 2014; Henshaw *et al.*, 2013), although positive perceptions appear to be most likely amongst midwives caring for women who declined to follow professional advice (Thompson, 2013; Wines, 2016). Negative experiences of supervision have been attributed to the dual role of SoMs in safeguarding standards of practice and supporting midwives (Calvert, 2014; Henshaw *et al.*, 2013). This overlap with regulatory processes was criticised in the review of statutory supervision of midwives in the UK (Baird *et al.*, 2015; Murphy, 2016), which has led to significant changes (Department of Health, 2016). Likewise, overlap between managerial and clinical supervision in employed practice contexts has also been criticised (Nipper & Roseghini, 2014). Therefore, RMCAs should be independent of Australian medical and midwifery regulatory authorities and employing health services.

The transformative and innovative potential of the RMCA also rests on this independence: the role is unlikely to be successful if it is fulfilled by a midwife or doula. While relationship-based care carries many benefits for women (Sandall *et al.*, 2016), the midwives in this study, including those practicing in continuity models, reported not always being able to assure women of respectful maternity care. While minimising the fragmentation of care may provide more opportunity to develop mutual trust (Dahlberg & Aune, 2013), women in caseload models of care still interact with other clinicians, at least during labour and birth. Also, caseload midwives continue to have contractual obligations to their employer that may clash with the woman's needs, and which may undermine the RMCA role. The RMCA role must not be, or be seen to be midwifery-specific, since any such alignment could invoke the inter-professional conflict that sometimes constrains maternity reform in Australia (MacColl, 2009). Likewise, although some women employ doulas, and evidence shows that independent support during labour and birth is beneficial (Bohren *et al.*, 2017), doulas are unlikely to be accorded status within the health service and their presence may actually provoke resentment from clinicians (Steel *et al.*, 2015), compromising their ability to mediate between the woman, clinicians and the health service.

The proposed role's focus is not on advocating for any one party, but on the practice of respectful maternity care: supporting women to navigate the health system, supporting both obstetricians and midwives in the provision of that care and in debriefing and reflecting on their experiences, and supporting the health service by providing a quality assurance mechanism.

Recommendation 4: Establish the RMCA role, independently of medical and midwifery regulation and employing health services, to serve as an independent third-party providing additional support, mediation, advocacy and quality assurance to the woman, clinicians and the health service.

Research

'Evidence-based medicine' (EBM) is a commonly used term in maternity services and healthcare more broadly referring to "the conscientious, explicit, and judicious use of current best evidence in making decisions about the care of individual patients" (Sackett *et al.*, 1996, p. 71). This sounds laudable and EBM has provided a lever that has seen, for example, routine pubic shaving and enemas phased out in most maternity settings (Oakley, 1996). There are numerous other examples, however, where the power to determine what 'counts' as evidence is "influenced by the professional projects of those making decisions" to the exclusion of women (Downe, 2015, p. 1). Such 'professional projects' are evident in the recent (mis)use of evidence by an Australian medical lobby group to question the safety of midwifery models of care, and similarly demonstrated in a review of the homebirth position statements published by midwifery and obstetric colleges, which found that these statements are the "end product of significant confirmatory bias" (Roome *et al.*, 2015, p. 1).

Evidence-based medicine, and particularly the esteem it attributes to randomised controlled trials (Sackett *et al.*, 1996), conceals the many layers of interpretation that sit not just between observation and application of trial results in clinical decision making (Goldenberg, 2006), but also the socio-cultural context in which research is conceived, planned, funded, conducted and reported (Wendland, 2007). Feminist scholars have argued that EBM has further marginalised women from their birth experiences, since the biomedical "belief in the objectivity of data make women's experiences vanish, and women's bodies dangerous sites from which fetuses must be rescued" (Wendland, 2007, p. 227). Although EBM may appear to challenge the authority of individual expertise, its appeal to the authority of evidence has served to reinforce medical dominance (Goldenberg, 2006), and "women are confronted with a pathological account of themselves of unimpeachable scientificity" (Murphy-Lawless, 1998, p. 24). Likewise, Bensing (2000, p. 19) argues that EBM is "essentially, doctor-centred," and serves to shift the focus on to medical interpretation of evidence and away from human relationships. Evidence-based medicine has become, if it was not always, one of the master's tools. Nonetheless, not only *can* EBM be reappropriated to serve feminist ends, achieving woman-centred reform in maternity services may depend on that reappropriation.

This thesis demonstrated that the methodological approaches most accepted in EBM make it very difficult for researchers to explicitly state an intention to use research to drive reform. Health Services Research (HSR), which focusses on supporting change within health services (Sheikh *et al.*, 2011) has often been dominated by the "biomedical paradigm and its social science offshoots" (Weber & Castellow, 2012, p. 2), where the artifice of objectivity leaves only limited capacity to tackle reform directly (Gilson *et al.*, 2011). Conversely, transformative research (of which feminist research is one example) bridges the activist-scholarship divide (Weber & Castellow, 2012).

But feminist research has often favoured qualitative methods that remain on the margins of EBM and HSR. Some feminist scholars argue that positivist, quantitative methods are innately patriarchal and should be eschewed entirely (Hesse-Biber, 2010), but others contend that it is not quantitative methods themselves, but how they are used that determines whether they are feminist (Miner-Rubino & Jayaratne, 2007). Indeed quantitative methods can do what qualitative methods cannot: produce data (that is, statistics) that are brief and readily communicable, demonstrate patterns across populations and most importantly, enable feminists to introduce social justice issues into mainstream debate (Miner-Rubino & Jayaratne, 2007). It is the last point that Miner-Rubino and Jayaratne (2007, p. 10) identify as the most important since "real social change" depends on researchers being able to "report our research findings in a way that will attract people's attention and convince them of the need for social change. Numbers and statistics talk, and they talk loudly and persuasively."

Just as obstetric and midwifery discourses are often at "cross-purposes" (Wendland, 2007, p. 227) and EBM and patient-centred care "belong to different worlds" (Bensing, 2000, p. 17), I suggest that HSR may be hamstrung by its reluctance to look beyond positivist approaches in order to engage in explicitly activism-oriented research. Each preaches only to its own converts. If researchers want their work to persuade clinicians and health services policymakers then, they must reappropriate the conventions of HSR and conduct research that directly drives change. James' (2009, p. 86) argument about using the master's tool concurs: "if we want to make music that a wide audience will actually listen to and enjoy, there seems to be no avoiding some of the 'master's tools.'" Although James' argument is developed in the context of performing arts, the same is true of conducting research with activist aims. Evidence is the currency with which change is purchased in contemporary maternity care; a feminist approach lies in transforming the ways that the evidence-base is produced, by whom and for what purpose.

As presented in Chapter Seven, Agenda-driven Research permits researchers to declare an activist agenda and use research to pursue reform. It applies the transformative paradigm to bridge the methodological gap between 'objective' HSR and 'activist' feminist research. Without an agenda-driven approach, researchers must disguise their activist intentions, which can lead to research divorced from practice, clinicians and healthcare consumers. Agenda-driven Research seeks to engage Freedman's (2016) "engine of change" in maternity services by conducting research that attends to the concerns of women, in ways that engage decision makers. By focusing on issues of concern to women, Agenda-driven Research places women at the centre and skirts the polarisation of obstetrics and midwifery that has plagued maternity care. As described in Chapter Seven, Agenda-driven Research is a legitimate approach available for researchers interested in reforming maternity care and maternity services.

This chapter has recommended the PACT process and an opportunity now exists for a prospective study to evaluate its utility and acceptability in practice. Such a study would partner with health services to pilot the PACT process, and thoroughly investigate the experiences and outcomes of women who use it, as well as its economic and bureaucratic impact and the acceptability of the process to key stakeholders (including women; midwives; obstetricians; health service managers; regulators; insurers and midwifery and obstetric organisations and maternity consumer groups). An Agenda-driven approach would again be needed to promote and test the PACT process with a mixed methods prospective cohort study that follows a cohort of women who intend to decline recommended maternity care.

Recommendation 5: Agenda-driven research be adopted by researchers interested in affecting health service reform, including in a future study of the utility and acceptability of the PACT process.

Conclusion

This thesis has answered the research question *Could a documentation and communication process support pregnant women's rights to decline recommended maternity care?* This question was explored through a retrospective review of MCP cases where women were documented as having declined recommended care, as well as in-depth interviews with women, midwives and obstetricians to investigate the utility of the MCP process and document the perspectives and experiences of women, midwives and obstetricians in situations where pregnant women decline recommended maternity care. In conducting this research, I also found that existing frameworks did not facilitate an activist orientation to HSR. I have therefore also described Agenda-driven Research, and offer it as a feminist response to the conventions of evidence-based medicine.

The MCP process purported to uphold women's rights to refuse recommended care and to whatever extent it achieved this, it relied on obstetric authorisation. In doing so, it was one of the 'master's tools' that sustain medical dominance. However, it was also this obstetric authorisation that enabled the MCP process to be recognisable to the workings of power within the hospital, and thus secure the woman's access to care. Nonetheless, a more woman-centred approach, the PACT process, has been recommended in this chapter as a way of reappropriating the master's tools in order to better support women's rights to decline recommended maternity care.

Woman-centred care is the widely-touted tenet of progressive healthcare policy in Australia (and abroad), but refusal presents something of an 'acid test' to that mantra. When women decline recommended care, clinician's must then provide care within the confines of the woman's consent, even where that carries an increased risk of poorer clinical outcomes and may be at odds with evidence-based clinical guidelines. Woman-centred care in that context is a difficult thing to deliver, especially where personal values and beliefs about the status of the fetus go unexamined. The challenge is further amplified by hierarchical, medicalised maternity services, where concerns about medico-legal exposure and professional censure may drive practice. Throughout this study, clinicians espoused respect for women's rights to refuse, much like they would likely all espouse an adherence to evidence-based practice (Downe, 2010; Goldenberg, 2006). Knowing the right thing to do is necessary, but not sufficient, for actually doing it. The challenge remains to find ways to make the right thing easy, or at least easier, to do.

Through an agenda-driven approach, this study concluded that although the MCP process was only partially and indirectly successful in supporting women's right to refuse recommended care, a refined process had the potential to be woman-centred and effective. The key characteristics of policy, practice, education, professional issues and research that underpin the PACT process have been outlined. By including the woman's voice in documentation, establishing flexible pathways for its initiation and the failsafe of a Respectful Maternity Care Advocate, the PACT process recommended here has the potential to make woman-centred, respectful maternity care for women who decline to follow professional advice easy, or at least easier, to do.

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Appendices

Appendix A: Chart audit data collection sheets

Chart Audit Data Collection Sheet A

Participant Code (created)	UR Number	To be collected only where consent to future contact about research is recorded.							
		Name	Address	Telephone number	Translation services needed?	Letter of Invitation sent	Follow up telephone contact	Agrees to participate?	Interview arrangement

Chart Audit Data Collection Sheet B

Participant Code	Date of Entry	Gestation at time of entry	Details of annotation in chart	Context of entry

Appendix B: MCP content analysis data collection sheet

MCP Content Analysis Data Collection Sheet

Participant Code: ____________________
Date of first visit: ____________________
Date of MCP: ____________________

Baby DOB: ____________________
Maternal DOB: ____________________
Date of discharge: ____________________

Reason for MCP	Nature of the non-standard care requested	Reasons for the request	Risks to mother discussed	Risks to baby discussed	Agreed care pathway
○ Request contrary to hospital policy					
○ Complex fetal condition ○ Complex maternal condition ○ Deteriorating condition of mother where delivery is in her best interests.	No further content analysis undertaken.				

Appendix C: Interview Guide

Interview Guide[11]

For interviews with women

The type of care sought

- Tell me about your maternity care at [study site], in particular about your Maternity Care Plan?
- What was 'non-standard' about your wishes for this birth?

Reasons behind the request

- Why was that important to you?
- Tell me about how you made your decision.
- Why did you want to avoid X?
- Why did you want to have Y?

Response from the hospital

- What happened when you first mentioned to your care provider that you wanted X?
- What happened when developed your MCP with the obstetrician?
- What was the process like for you?
- What were the good things about that process for you?
- What were the not so good things about that process for you?

Outcomes of the request

- What arrangements did you ultimately agree on in your Maternity Care Plan?
- How did these arrangements work out during your labour and birth? What was that like for you?

Maternal satisfaction

- Were you happy with the way that care providers implemented your MCP or were there things you would have changed about the way you were cared for?
- How do you feel about the process of developing a MCP now?
- Is there anything else you would like to share?

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[11] This interview guide uses the terminology 'requesting non-standard care' as this was consistent with the MCP policy documentation at the study site. Elsewhere in this thesis I prefer the phrase 'declining recommended maternity care,' as discussed in Chapter One.

Demographics

- Which age range best describes you? 18-25; 26-35; 36-45; 46-55; 56-65; >65
- What is your occupation?
- How many children do you currently have?
- For which of your births did you request non-standard care? (first, second…)

For interviews with maternity staff

Types of non-standard maternity care that women have requested

- Can you tell me about a situation where a woman has requested non-standard care?
- Can you tell me about the range of requests for non-standard care that you've been involved with?
- In what ways have you been involved with requests for non-standard care at MMH?
- How common would you say those situations are?

Reasons women seek non-standard maternity care

- Why do you think women decline standard care?
- What do you think drives women to request non-standard care?

Reactions, concerns and decision making when considering requests for non-standard maternity care

- [For obstetrician participants] What are your main worries when developing an MCPs with a woman?
- [For obstetrician participants] Have there been times when you just can't reach agreement with a woman? What happens then?
- [For obstetrician participants] Is there 'a line in the sand', things that you just can't agree to? Should there be? How do you decide?
- Are there examples that you can think of where women's requests for non-standard care should be disregarded?
- Who is legally responsible for the woman's care when if there is an adverse outcome from non-standard care?

Reactions, concerns and decision making when providing non-standard maternity care

- For you as a care provider, how is a non-standard care situation different?

Awareness, understanding and thoughts about the significance of relevant MCP policy.

- How familiar are you with the MCP policy on providing non-standard care? Can you tell me about it?
- What do you think of the MMH policy on providing non-standard care??
- Has the implementation of the non-standard care policy changed practice at MMH? If so, how? If not, why not?
- Have you previously worked or do you currently work in other maternity services? If so, what has been your experience of responding to women's requests for non-standard care?
- Is there anything else you would like to share?

Demographics

- Which age range best describes you? 18-25; 26-35; 36-45; 46-55; 56-65; >65
- What is your gender?
- What is your occupation at [study site]?
- How long have you worked at [study site]?
- How long have you worked as a/an [occupation], including before you commenced at [study site]?

Appendix D: PACT Template

PACT Template

The Personalised Alternative Care and Treatment (PACT) process can be used to support documentation and communication when a woman declines recommended maternity care. It is completed jointly by the woman (grey sections) and her care providers (white sections). The PACT template[12] may be completed in a single meeting, or over time; each entry should be dated and signed. Where multiple maternity care providers are involved, multiple copies of PART 1 can be completed.

Part 1: Record of discussions and advice

To be completed by the woman: Describe the situation, including your reasons for declining recommended care and what, if any, information, evidence or concerns you have considered in identifying your preferred care pathway.
What questions or concerns do you have?
To be completed by maternity care provider: What care is recommended in the woman’s situation? What maternal risks and benefits of recommended care have you discussed with the woman? What fetal risks and benefits of recommended care have you discussed with the woman?
What alternatives to recommended care have you discussed? What maternal risks and benefits of these alternatives have you discussed with the woman? What fetal risks and benefits of these alternatives have you discussed with the woman?

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[12] The development of this template was based on the findings of this research, and informed by Kotaska (2017) and the Australian College of Midwives (2014).

What written information or evidence have you provided to the woman to support her decision making in this situation? What advice have you given the woman verbally?			
Describe the boundaries, as you understand them, of what the woman is consenting to and what she is declining?			
To be completed by the woman What is your understanding of the advice and answers to questions you have received from your maternity care provider? Is there anyone else with whom you would like discuss your ongoing maternity care?			
To be completed by the clinician: Under what circumstances will these discussions be revisited?			
With whom have you consulted about the woman's ongoing care?			
Name	Date	Position	Details of consultation
What actions have you taken as a result of the above consultation?			
Documentation reviewed consultant obstetrician:			
Name	Signature	Date	Details of consultation. Specify what, if any, further actions are needed and who will undertake those actions.

Part 2: The PACT

Following the discussions documented in Part 1, outline the plan for the woman's ongoing maternity care. Include indications of when and under what circumstances this plan will be reviewed, and by whom.

Woman's declaration

- I have been informed of the risks, as documented above, to myself and my fetus of the plan described in this PACT.
- I expect to still receive respectful, professional care.
- I have the right to change my mind and consent to recommended care at any time.
- I accept that my maternity care providers may refuse to perform an intervention that they believe to be unsafe; however, intrapartum care and attendance in labour are not interventions. My maternity care providers will continue to provide me with care to the best of their ability within the confines of my consent.
- **I understand that neither this PACT, nor my care providers' ongoing treatment of me are an endorsement of my intended care. Instead, in signing this PACT and agreeing to continuing treating me, my maternity care providers are only respecting for my right to choose.**
- **I accept that I am legally and ethically responsible for the outcomes that result from my decisions documented in this PACT.**

Woman's Name	Signature	Date

Maternity care providers' declaration

- I have provided the woman with objective, unbiased, current and accurate information about the risks to herself and her fetus of the course of action documented in this PACT.
- I will continue to provide respectful, professional care.
- I acknowledge that the woman has the right to change her mind and consent to recommended care at any time. I will inform the woman of any changing clinical circumstances that may alter her level of risk or otherwise influence her decision making.
- I will refuse to perform an intervention that I believe is unsafe; however, intrapartum care and attendance in labour are not interventions. I will continue to provide care to the best of my ability.
- **In agreeing to continue to provide care, I am not endorsing the woman's choice; rather I am respecting her right to choose.**
- **I acknowledge that the woman is legally and ethically responsible for the outcomes that result from her decisions documented in this PACT. I remain legally and ethically responsible for providing care to the best of my ability within the confines of the woman's consent.**

Care provider's Name	Role	Date	Signature
Care provider's Name	Role	Date	Signature
Care provider's Name	Role	Date	Signature